Predictors of Distress and Coping in Children with Unusual Experiences the Role of Stigma and Appraisal

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SUMMARY OF CONTENTS

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Service Evaluation

An Evaluation of the “Coping with Distress Group” in a Community Learning Disability Team

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ABSTRACT

Psychological therapy for mental health problems in people with learning disabilities has a slowly growing evidence base. The use of groups within the population would help reduce referral to treatment time, would fit with stepped care models and would provide equity of treatment access to which this population has a right (Disability Discrimination Act 2005; NICE, 2011). This service evaluation describes the introduction of a coping strategies group delivered to clients on the waiting list for individual therapy at an outpatient psychology service for adults with learning disabilities in Lewisham. Results, recommendations and limitations of such practice-based evaluations are discussed.

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1. INTRODUCTION

1.1 Mental Health in Learning Disabilities

It is estimated that 828,000 adults in England are affected by a learning disability, although only 177,000 are believed to be known to learning disability services (Emerson & Hatton, 2008). Within this population the prevalence of mental health problems is similarly uncertain but has recently been estimated at over a third of the learning disabled population (Cooper, Smiley, Morrison, Williamson & Allan, 2007), much higher than in the general population (Singleton, Lee & Meltzer, 2002). Whilst problems with the reliability and validity of diagnosing mental health problems in people with learning disabilities have been well documented (Einfeld & Aman, 1995; Hatton, 2002; Moss, 1995, 1999), these findings highlight the need for services which respond to the mental health needs of people with learning disabilities.

Whilst the understanding and treatment of people with learning disabilities has shown considerable progress over time (Harris, 2006), they remain a relatively neglected group in terms of research into, and treatment of, mental health problems (Hatton, 2002). Sir Jonathan Michael (2008, p. 7) went further in his report, *Healthcare for All*, stating that people with learning disabilities "have higher levels of unmet needs and receive less effective treatment," in spite of the right to equality of service provision as set out by the Disability Discrimination Act 2005. The UK government has responded to this, reiterating and elaborating its vision for supporting people with learning disabilities (DoH, 2001, 2009). The latest recommendations for the assessment and treatment of common mental health problems also promote (albeit briefly and non-specifically) equivalent forms of treatment for people with and without learning disabilities who have mental health problems (NICE, 2011).

1.2 Evidence Base for Treatment

Possible reasons for the historically slow development of a research base in the treatment of mental health problems for the learning disabled population include difficulties in diagnosis and previously held assumptions about the ability of this population to engage in therapy (Benson, 2004). Diagnosis of mental health problems is complicated by the fact that an assessment often relies on the verbal description of inner states by the client or inferring these states from observable behaviour (Hatton, 2002). In people with learning disabilities the ability to accurately describe one's inner states may be compromised and the idiosyncrasies of one's learning disability may mask behaviours expressing mental health problems (Einfeld & Aman, 1995; Hatton, 2002). This presents problems for research, as treatment programmes are

usually targeted at a specific disorder; without sufficient reliability in the diagnosis of such disorders the validity of the treatment programme is called into question. Nonetheless, evidence suggests that reliable diagnosis of mental health problems is possible and even existing self report measures can be successfully used or adapted to aid assessment of people with learning disabilities (Einfeld et al., 2007; Lindsay & Skene, 2007). With regards to engagement in therapy, it has been suggested that mental health professionals in the past commonly viewed talking therapies as being inaccessible to people with learning disabilities (Hurley, 1989). However, notwithstanding claims that behavioural techniques are being incorrectly labelled as cognitive techniques (Sturmey, 2004), numerous studies have demonstrated an ability of the learning disabled population to engage with the concepts and process of cognitive behaviour therapy (CBT), especially with appropriate support (Dagnan, Chadwick & Proudlove, 2000; Hurley, 1989; Sams, Collins & Reynolds, 2006; Willner & Goodey, 2006; Willner, 2006).

Evidence is emerging of the utility of psychological therapies for people with learning disabilities. However Beail (2003) notes that, although promising, much of this evidence both within CBT (described below) and psychodynamic psychotherapy (e.g. Beail & Warden, 1996) is based on case series or studies of small numbers with insufficient power to compare groups, a view supported by other authors (Bouras & Holt, 2004; Chaplin, 2004; Willner, 2005). He also notes that studies in this area are usually conducted in clinical service settings and should therefore be viewed as "practice-based evidence rather than evidence-based practice" (p. 471). This should not, however, detract from the existing evidence base, as both approaches contribute to the development and proliferation of effective interventions; rather what he argues is that more rigorously designed research studies are required to obtain the sufficient power, validity and reliability to support the use of psychological interventions in this population.

CBT has an extensive evidence base for the treatment of various problems from insomnia to psychosis in the general population (Abramowitz, 1998; Bastien, Morin, Ouellet, Blais & Bouchard, 2004; Clark et al., 2003; DeRubeis et al., 2005; Peters et al., 2010). For people with learning disabilities, CBT appears to have its strongest evidence base within anger management (Benson, Rice & Miranti, 1986; Rose, Loftus, Flint & Carey, 2005; Willner, Jones, Tams & Green, 2002). However, limited evidence does exist in the form of case studies that CBT can be used to treat depression (Lindsay, Howells & Pitcaithly, 1993) and anxiety disorders such as obsessive-compulsive disorder (Willner & Goodey, 2006) and specific phobias (Newman & Adams, 2004).

Group interventions for people with learning disabilities have gained increasing attention recently. In a survey of UK Psychologists working in learning disability services, Heneage and Neilson (2012) found that the most common type of group run in such services was for anger management, closely followed by groups for relationships and social skills or communication. This is perhaps unsurprising, given that anger management is one of the most researched areas for both individual (Willner et al., 2002) and group (Benson et al., 1986; Hagiliassis, Di Marco, Young & Hudson, 2005; Kaur, Cawley, Lewis & Morris, 2009) therapy in this population. While group interventions for specific problems such as depression (McCabe, McGillivray & Newton, 2006), anxiety (Dixon & Gunary, 1986; Turk & Francis, 1990) and bereavement (Boyden, Freeman & Offen, 2010; Clute, 2010) have been reported, Heneage and Neilson's (2012) survey suggested that it was more common in learning disabilities services for groups to focus more on skills or education. This may be due to the diversity of presenting difficulties with which a group of clients with learning disabilities may present. Nonetheless, group formats have reportedly been successfully adapted to address diverse presenting difficulties in the same group with comparable results to usual individual treatment (Jackson, 2009). Whittall and Courtney-Brisbane (2012) outline some suggestions for creating groups for people with learning disabilities, although much of the advice given could be usefully applied to groups in any setting, such as the consideration of client needs, barriers to attendance and pacing of sessions.

Currently, the favoured theoretical orientation for group interventions in learning disability services appears to be CBT (Heneage & Neilson, 2012). This is also perhaps unsurprising given CBT is commonly recommended by the National Institute of Health and Clinical Excellence (2011) and has a broad literature supporting its use in the general population (e.g. Shaffer, Shapiro, Sank, & Coghlan, 1981). Within learning disabilities the evidence is again often limited to case studies, but a growing body of research supports the use of CBT-oriented groups with various foci. Whelan, Haywood and Galloway (2007) conducted a five person CBT group to improve self-esteem and reported some improvement in this area. However, the measure used, while adapted from the Rosenberg Self-Esteem Scale (Rosenberg, 1965), was not validated and two clients reported high self-esteem from the start in spite of the fact participants were supposedly selected on the basis of having low self-esteem. Bereavement groups have been commonly presented in the literature (Boyden et al., 2010; see also Clute, 2010 for a review) and so far suggest promising results based on qualitative and quantitative outcomes, though more formal measurement is suggested. Randomised controlled trials are rare; McCabe and colleagues (2006) conducted one such trial of group intervention for

depression for people with mild to moderate learning disabilities in Australia. They found significant improvement of depression, social comparison and frequency of negative automatic thoughts post-intervention, though only social comparison was improved compared to the control group. However, they also found a greater number in the treatment group achieving substantial (i.e. >3) improvement in scores and fewer experiencing deterioration in scores than the control group. This type of study demonstrates that controlled trials of treatment groups are possible and can help to build a foundation of evidence on which services can base their interventions.

Group interventions based on other theoretical orientations have also been reported. Gravestock and McGauley (1994) ran a year-long psychodynamic group with nine clients with varying levels of disability. They reported themes such as dependence and loss as being prominent in the group and reported positive qualitative outcomes such as improved communication and greater self-acceptance. O'Connor (2001) also reported a group intervention based on a group-analytic approach. This highlighted similar themes of dependence but also of ambivalence, demonstrated by multiple drop-outs from the group. This group ended prematurely and it is suggested in a later paper that this was due to a lack of support from the service (Rye, 2012). After drop-outs the group was being run with only two clients, which the service may have felt was unsustainable. Humanistic approaches have also been reported. Shechtman and Pastor (2005) compared a CBT-based and humanistic group for children with learning disabilities in Israel. They found that those children in the humanistic group achieved improved learning, reduced self-reported externalizing behaviour (although not teacher-reported) and less social rejection compared to academic support alone and, in some cases, compared to the CBT group. Some groups report using a 'hybrid' approach, combining theoretical orientations such as psychodynamic and CBT principles. Gregory and Heneage (2012) combined the psychoeducation and maintenance models of CBT with the use of group processes present in psychodynamic therapies and provide useful guidance and reflections on the running of such a group; however they do not report any outcome data. Groups based on other orientations have been suggested, such as third wave therapies (Thomas, 2012; Williams, 2012) but, as with the approaches outlined above, much more research is needed to develop evidence-based practice.

1.3 The Stepped Care Model

Despite the call for further research on the treatment of mental health problems in learning disabilities being almost as strong now as it was over twenty years ago, the existing evidence and requirement for equal access to treatment suggests that both individual and group CBT

treatments can and should be offered to clients with learning disabilities who experience mental health problems. One reason for the increasing focus of services on group treatment is the greater efficiency in time and cost it provides. Mental health service provision in the UK is now recommended to be based on a stepped care model (NICE, 2011). While the number and nature of individual steps vary, they can be broadly grouped into the following categories:

Table 1: An example of levels of intervention in a stepped care model

	Broad Category	**Nature of Intervention**
Minimal service use ↓	Minimal primary care involvement	Assessment, psychoeducation and monitoring
	Minimal secondary care involvement	Group treatments, short term individual therapy, self-help groups/workshops, supported/computerised self-help
	Secondary care involvement	Longer term individual therapy, facilitated groups, possible care-coordination from community mental health teams
Intense service use	Tertiary and intensive involvement	Inpatient services, enhanced Care Programme Approach (CPA) management

The stepped care model is designed to improve the efficiency of mental health service provision by offering the most appropriate, cost-effective service available to the client. Clients are typically assessed in triage and assigned to lowest appropriate step depending on their needs. If this step is found to be insufficient to meet the client's needs, they can be 'stepped-up' at any time to a more intensive treatment. If, however, the lower step is found to be effective for the client, then significant time and money will have been saved by not automatically providing weekly individual therapy with a Clinical Psychologist. The other advantage to the stepped care model is its affect on waiting times. The Department of Health (2011) continues to hold 18 weeks as the standard target for referral-to-treatment waiting times in its Operating Framework. However, it has been suggested that services commonly fail to meet this standard and the stepped care model has been promoted as one possible solution to this (Bower & Gilbody, 2005; Lovell & Richards, 2000; Richards, Lovell & McEvoy, 2003).

1.4 Rationale for The Present Evaluation

This service evaluation focuses on the delivery of a CBT informed group intervention for adults with learning disabilities awaiting individual therapy with an outpatient psychology service in

Lewisham. The group was conceived as a response to long waiting lists within the service (around eight months at the time the group started) with the aim of reducing the referral to treatment time, providing equity of access to services for clients and reducing risk for clients on the waiting list.

As described above, CBT group programmes are usually targeted at specific diagnoses, or at developing specific skills. The problem encountered by this team was an extended waiting time for clients with a variety of presentations that did not fall neatly into specific diagnostic groups. Therefore the running of several groups according to presentation was not a viable option to offer clients who were facing long waiting times for individual intervention. The challenge was to strike a balance between offering an intervention in a timely fashion, managing risk while on the waiting list, and providing efficacious therapy to clients with diverse presentations. In the absence of sufficient numbers of similar presentations to run diagnosis-specific groups, a group was set up with a focus on coping skills (within a CBT framework) in a similar vein to the groups described by Heneage and Neilson (2012). This was viewed to be the most pragmatic way of addressing the issues facing this team and similar interventions for individuals with learning disabilities have been reportedly previously as part of a stepped care model (e.g. Jackson, 2009).

Using the concepts of "stress and coping" as the focal points of a therapeutic group may appear non-specific by the standards of the individual guidelines for the treatment of specific disorders; however, the concept of coping as influencing psychological wellbeing in the face of everyday stressors stretches back to the 1970's (Folkman & Lazarus, 1980; Pearlin & Schooler, 1978). Lazarus and colleagues' cognitive phenomenological theory of psychological stress also shares some key characteristics with the currently popular CBT approach (Lazarus, Kanner & Folkman, 1980). This theory posits that the cognitive and behavioural responses of a person mediate the effect of an event on that person. These responses include cognitive appraisals of the significance of the event and possible coping responses and coping behaviour. Multiple subdomains of coping have been posited and researched in the literature but most coping responses can be broadly categorised as emotion-focussed (where the aim is to manage the emotional response to the distressing event) or problem-focussed (where the aim is to practically address and try to solve the problem) (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Emotion-focussed coping has been found to be associated with less distress while the effect of problem-focussed coping has been positive but non-significant, both within everyday and complex problems (Folkman & Lazarus, 1986; Li, Cooper, Bradley, Shulman, & Livingston, 2012). However early categorisations of coping responses did not routinely include

behaviour which may be associated with greater distress, or at least prevent engagement in adaptive coping responses (Carver, Scheier & Weintraub, 1989). For this reason, Carver and colleagues (1989) added a dimension of dysfunctional coping for their measures of coping styles, the COPE.

2. METHOD

2.1 Participants

Participants were selected from the waiting list for individual therapy within the service. Twenty-nine service users were on the waiting list at the time of selection. Participants were excluded if the client had been recommended for behavioural intervention following initial assessment (n=13), if they were presenting with flashbacks (n=1) or if they were expected to start individual therapy over the period of the group (n=7). Eight participants were therefore invited to join the group, of which five attended.

2.2 The "Coping with Distress" group

The group was developed by two Clinical Psychologists within the Lewisham Mental Health in Learning Disabilities Psychology Team. It was based on the CBT principles described above and consisted of eight weekly, hour long sessions facilitated by these two clinicians, which ran from January to March 2012. The group may be best conceptualised as fitting with the self-management approach described by Dagnan and Chadwick (1997), where participants are supported in developing skills to improve self-instruction and self-regulation. While the longer term plan is to consider a stepped care approach where group therapy is offered as an alternative to individual therapy, this group was introduced as an additional service for those on the waiting list for therapy. The reason for this was that, as a new service, depriving clients of individual therapy before the group has been properly evaluated could be detrimental.

2.2.1 *Outline of the group*

The format of the group was as follows:

Session 1: Introductions, ground rules and goals drawn up as a group, introduction to relaxation using CD, copies of CD given to participants to take home and outcome measures completed.

Session 2: Finished outcome measures, discussed common emotions (low mood, anger, anxiety) and drew up physiological responses to emotions on body chart. Finished with relaxation CD.

Session 3: Recap of ground rules for new group member, continuation of session 2, group members draw up physiological responses to emotions for themselves. Relaxation CD.

Session 4: Psychoeducation on thoughts, feelings and behaviours. Examples of positive and negative thought-feeling-behaviour cycles drawn up. Group members drew up

their own cycles and were given further sheets to complete for homework. Relaxation CD.

Session 5: Recapped homework. Continued discussion of thought-feeling-behaviour cycles, then discussed coping strategies, including separating out adaptive and maladaptive. Relaxation CD

Session 6: Introduced and practiced coping strategies. Distraction, visualisation, breathing exercises, positive self-statements practised in session and given as homework. Relaxation CD

Session 7: Recapped homework and further practice of coping strategies in session. Discussed individual therapy and similarities and differences to group work. Facilitators role-played snap-shot of typical therapy session. Relaxation CD.

Session 8: Recapped coping strategies. Completed outcome measures and distributed prompt cards and folders of their work to each member.

2.2.2 *Materials*

The principle material through which the group was delivered was a flip chart and markers. Group discussions on, for example, thoughts, feelings and behaviours or bodily sensations were summarised on flip charts. Pages summarising each discussion were then attached to the walls of the group room and reattached in the same place at the start of each session. These pages consisted of contributions from all group members and individual members were given A4 sheets on which they could summarise parts of the discussion which were relevant to them. For example, when discussing bodily sensations, a sketch of a body was drawn on the flip chart and various sensations were drawn onto it from suggestions by the group. Group members were then able to complete their own version, selecting the bodily sensations which were relevant to them. These individual sheets were kept by members in their own packs. As a reminder of the overall discussion, copies of the flipchart were also made in A4 format and handed out to group members.

2.3 Outcome Measures

Three outcome measures were completed in the first and final session. They were then sent out to all participants three months after the completion of the group. In the group, they were issued in questionnaire format and were filled out with the support of the facilitators.

2.3.1 *Psychological distress*

This was measured using an adapted version of the Clinical Outcomes in Routine Evaluation - Outcome Measure (CORE-OM) for use with people with learning disabilities. This measure is

adapted from the GP-CORE (Evans, Connell, Audin, Sinclair, & Barkham, 2005), a shorter and more positively worded version of the CORE-OM (Evans et al., 2000). This 14-item measure assesses domains of functioning, problems or symptoms and well being, with responses given on a five-point Likert frequency scale (0= never; 4= most or all of the time). Scores are calculated by averaging responses given within a domain and overall (minimum and maximum possible scores are 0 and 4 respectively). Higher average scores indicate more reported difficulties within a domain. The version utilised by the service uses a histogram visual rating scale and is similar in its delivery to the LD-CORE (Marshall & Willoughby-Booth, 2007). This questionnaire is a required outcome measure for all treatment carried out within the service.

2.3.2 *Subjective quality of life*

This was measured using the World Health Organisation Quality of Life (WHOQOL-8) EUROHIS-QOL8 (Schmidt, Mühlan, & Power, 2006; The WHOQOL Group, 1998). This 8-item measure is a brief quality of life questionnaire covering domains of psychological, environmental, physical and social well being. It assesses subjective life satisfaction within these domains using a five-point Likert scale response format, with higher scores indicating greater perceived quality of life (minimum possible score = 8; maximum = 40). The scale was adapted for use with people with learning disabilities by use of cartoon faces depicting different levels of happiness in each domain. This questionnaire is also a required outcome measure for all treatment carried out within the service.

2.3.3 *Coping*

A 16 item coping strategy questionnaire was developed by therapists within the service in response to the lack of a validated, accessible coping strategies questionnaire for people with learning disabilities (see Appendix 1). This was developed in order to measure any changes in the use of coping skills, which was the target of the group. The measure was broadly similar in question content to the Brief COPE (Carver, 1997). However, due to the lengthy nature of completing outcome measures (and the service requirement to complete the questionnaires listed above), the measure was reduced to 16 items. As such, it was not possible to separate questionnaires into categorical coping scales. Instead, questions were grouped simply into adaptive (minimum possible score = 0; maximum = 40) and maladaptive (minimum possible score = 0; maximum = 24) coping styles. The measure was also adapted to be accessible to people with learning disabilities through the use of photos (Photosymbols 3) and a histogram visual rating scale similar to that used for the LD-CORE (Marshall & Willoughby-Booth, 2007). The choice of photos to represent each coping concept was agreed by the two group leaders and a Trainee Clinical Psychologist (JB).

2.3.4 *Therapy use*

Participants' use of individual therapy was monitored following the group. This information was gathered by one of the group leaders within the team and anonymised. While unlikely to be directly comparable to average treatment durations for the service as a whole due to the small sample, this will contribute to any further data for comparison.

2.4 Feedback

At the end of the sessions each participant was given a 3-item feedback questionnaire asking what they liked about the group, what they would change and which techniques they intended to continue using in the future. A group discussion was also held on the same topics to allow those participants who so wished to elaborate on their feedback or clarify how the group could be changed for future participants.

3. RESULTS

3.1 Demographics and Attendance

Five participants attended the group (4 female, 1 male). The mean age of the group members was 33 years (s.d.= 9 years; range= 22-43 years). The participants were from a diverse range of ethnicities (1 white British, 1 black British, 1 Arab and 2 African – other). The average number of attendees per session was 2.88 (range= 1-5) and the average number of sessions attended by each participant was 4.6 (range= 3-6). Participant 1 started the group at session three due to a hospital admission and participant 5 joined the group at session four after arriving too late to join at session three. Follow-up data was returned by participants 1, 3 and 5 only.

3.2 Outcome Measures

3.2.1. *CORE-OM*

Pre-post and follow-up data are shown in Figure 1. All participants reported some improvement in overall score at either post-intervention or follow-up, though for most participants this improvement was subtle.

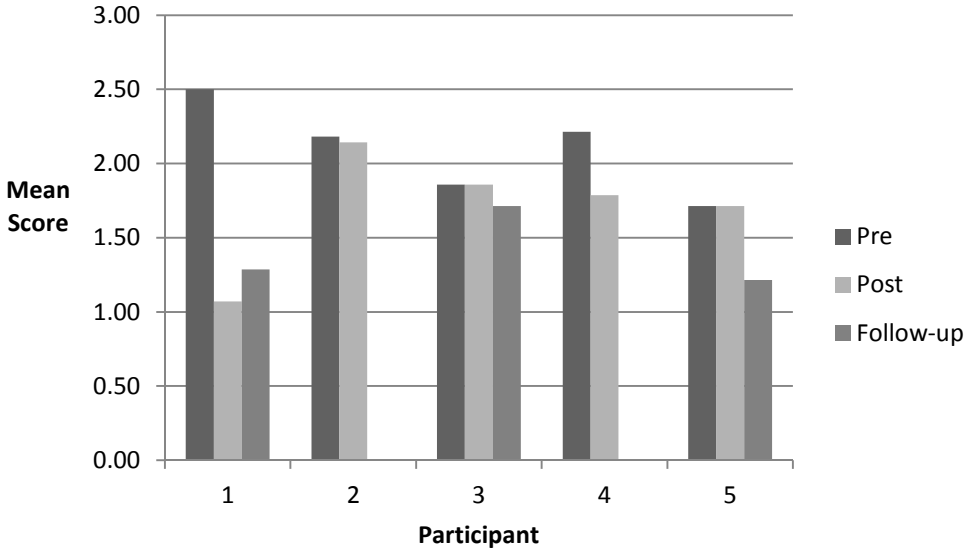

Figure 1: Mean overall CORE-OM scores

Mean scores for each domain of the CORE can be seen in Figures 2-4. Again, higher mean scores indicate more perceived problems in each domain. Across these domains it appears that the greatest and most consistent improvement was in the functioning domain. Scores in the problems domain present a more mixed picture and in the wellbeing domain participants appear to report greater or unchanged difficulties following the intervention[1].

[1] Participant 5 returned follow-up data and scored 0 at all three time-points on the wellbeing domain whereas participants 2 and 4 did not return follow-up data.

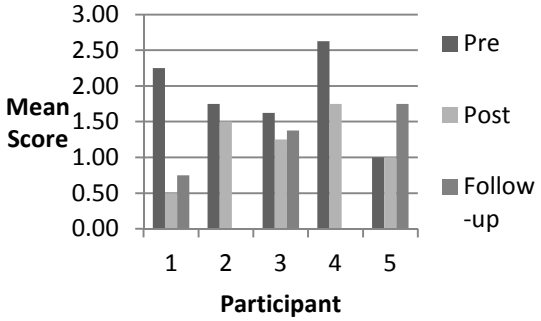

Figure 2: CORE-OM mean functioning scores

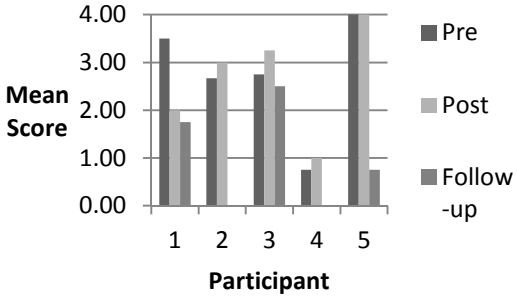

Figure 3: CORE-OM mean problem score

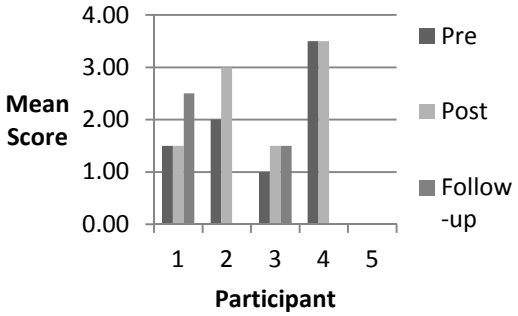

Figure 4: CORE-OM mean wellbeing scores

3.2.2 *Quality of life*

The majority of group participants reported subjective improvement in their overall life satisfaction by the end of the group, though the follow-up data presents a more mixed picture (see Figure 5). The largest and most consistent improvement in scores between pre-intervention and either post-intervention or follow-up was in the psychological domain, particularly in the question asking how happy people were with themselves. In this question, all but one participant recorded a two point improvement after the intervention.

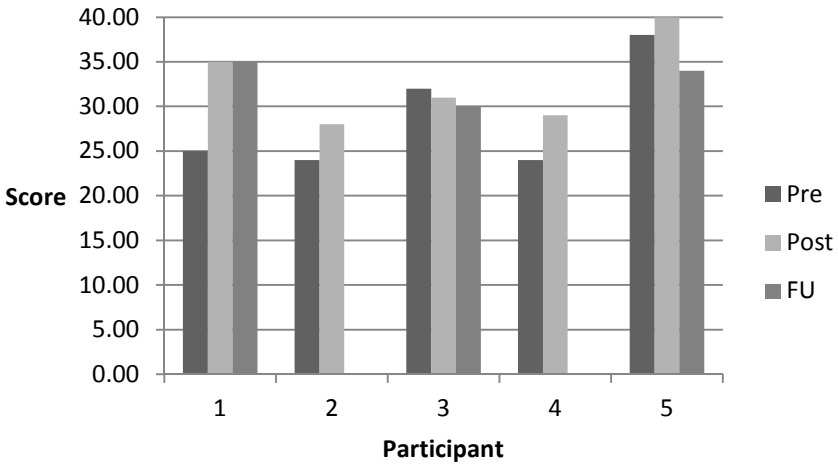

Figure 5: WHOQOL scores

3.2.3 *Coping*

Frequency of use of adaptive and maladaptive coping strategies are shown in Figures 6 and 7. Again this shows a mixed response to the intervention, with the greatest change coming from participant 1 in a positive direction but both participants 2 and 3 reporting negative changes in the use of coping strategies.

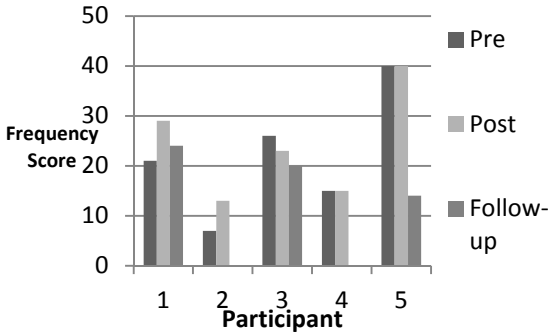

Figure 6: Use of adaptive coping strategies

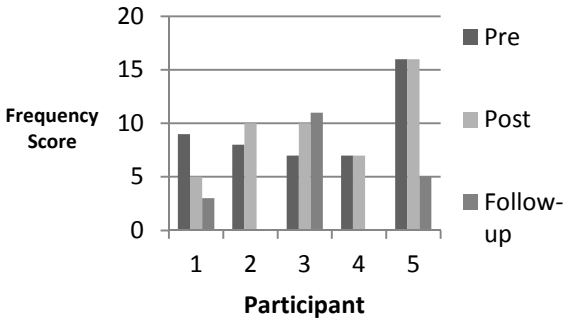

Figure 7: Use of maladaptive coping strategies

3.2.4 *Later individual therapy use*

All five participants went on to enter individual therapy. Two participants (3 and 5) were closed by the service after five sessions, one by mutual consent as the work was deemed completed and one by disengagement. One participant (2) attended three sessions and elected to discontinue therapy when their therapist left; they were therefore closed but re-referred for the same presenting problem four months later. One participant (1) engaged in six sessions of therapy before moving out of the borough and being handed over to another team; it was noted at handover that the presenting problem was reported to no longer be an issue early on in therapy. Only one participant (4) remained continuously open to the team after one year. They attended six sessions of individual therapy before disengaging and were instead offered a systemic approach.

3.3 Feedback

All five participants provided feedback to all questions on the questionnaire and contributed to the group discussion. Participants mostly responded that they liked the interpersonal aspects of the group, such as meeting people, being able to talk about their problems and being listened to. One participant noted that they liked learning about feelings. The majority of participants said they would change nothing about the group in the questionnaires; however the group discussion elicited more suggestions. It was a suggested that a telephone call or text prompt would help remind people of the group and that more notice before starting the group

might have improved uptake (2 weeks notice was given before the start of this group). One participant also thought more handouts would be helpful.

During the discussion on changes, participants were asked specifically about certain aspects of the group and whether they would change them. Participants agreed that they would not change the location of the group as they liked that it was not in a hospital. It was also fedback that the time spent filling out outcome measures was not excessive. They also reported that the length of the sessions (one hour) was appropriate and that they did not feel the need for a break. The format of the group was such that early sessions were more information based and later sessions were more skills based. Participants were asked whether they would prefer the skills based elements to be more evenly spread across the group but this received a mixed response, with some for and some against this idea. Relaxation exercises were identified as the technique most likely to be reused following the group, though one participant said they did not like these.

4. DISCUSSION

4.1 Conclusions and Limitations

In the feedback questionnaires and group discussion participants appeared generally positive about the group. However, the outcome measures present highly mixed findings, with minor improvements suggested in distress (particularly in the functioning domain) and quality of life but variable changes in the use of coping strategies. It is clear that more data is required before conclusions can be drawn about the effectiveness of the group and the current data suggests that further investigation would be worthwhile. In the feedback, it was widely noted that relaxation was the technique most likely to be used in the future. While is it is promising that there was something from the group which participants widely felt they could take away and use again, relaxation techniques are perhaps limited in their utility in everyday stressful situations, especially longer practices which may not be practical in dealing with stress 'in the moment'. Relaxation was, however, the most frequently repeated exercise, which may explain why it was the most likely to be used again. A consideration for future groups may be which techniques are most likely to elicit lasting change and whether these techniques are the ones most often repeated or recapped in sessions.

Based on the inclusion criteria, eight people were eligible to join the group. However, only five attended and two of these participants arrived at the third and fourth session. The average number of sessions attended was only just over half the number delivered, which is likely to limit the effectiveness of the group. Improving attendance to the sessions is therefore important if further investigation is going to draw firmer conclusions about the effectiveness of the intervention. Suggestions of how to increase attendance and uptake of sessions is presented below in the recommendations from this pilot group.

Although all five participants provided pre and post data, it does appear that participant 5 tended towards last option responding in the pre and post CORE and coping measure and first item responding in the EUROHIS-QOL8. While this cannot be certain, as no items are directly contradictory (in order to reduce the question load), the spread of responses appear to fit this pattern by virtue of the fact that they scored maximally on almost every scale, whether positively or negatively worded, except where certain items give a reversed score. This further reduces the ability to draw conclusions from the data provided by the other four participants. It was observed that the participant who appeared to show the most improvement across the three time-points (participant 1) was the same participant who attended the most sessions.

However, no association can be drawn between session attendance and improvement without further data as there may have been certain characteristics of the participant which made them both more likely to attend and more likely to improve (for example, they may have been more motivated, leading them to attend more sessions and be more likely to use the techniques learned in session).

The limitations of this service evaluation in terms of participant numbers have been described above; however, there is further limitation of the follow-up data. As the group was provided as an adjunct to individual therapy rather than a replacement, all group members who returned three month follow-up data had started individual therapy by the time of their follow-up. Only one group member (participant 4) had yet to start therapy at follow-up, but they did not provide data. While follow-up data does not appear to deviate greatly from post-intervention responses, it may be that individual therapy maintained or compounded any improvement in participants' scores. While both the EUROHIS-QOL8 and the CORE-OM are well validated in various populations, validation in learning disabled populations is lacking; the coping measure used similarly lacks validation in the target population. Gathering of further data will allow for investigation of the psychometric properties of these measures, which will be important for their further use as validated versions of such measures are lacking in this population. Another possible limitation may be that, given the fact that the coping questionnaire openly probes the use of coping strategies learned in the group, responses at the end of therapy may be susceptible to a desirability bias. However, there was nothing observed by the group leaders to suggest that participants' responses were affected by this. The open discussion of feedback suggests that participants felt comfortable reporting aspects of the group which they felt were less helpful, which would suggest a reduced influence of desirability bias.

4.2 Recommendations

Based on the service evaluation, the following recommendations are made for the 'Coping with Distress' group:

- The group should be repeated in order to obtain more data on its efficacy. Since there is still insufficient evidence of effectiveness for the group to be offered as an alternative to individual therapy, the group should be run similarly to its first operation, as an adjunct to therapy for participants on the waiting list.

- Should the group be found to be effective in future trials, a further evaluation may be useful to assess as to whether participation in the group reduces the need for individual

therapy, for example, by reducing individual treatment time compared to waitlist only. If this were to be the case, the service could legitimately move to offer the group as a 'lower intensity' alternative intervention to individual therapy, thereby applying a stepped care model to treatment within the service.

- Eligibility to attend the group should be established during the initial assessment for the service and, where appropriate, the group intervention should be offered at this point. This may improve the uptake of the group in the first instance.

- In accordance with the feedback provided by participants, clients should be given advance notice of the group (for example, at assessment and then possibly again nearer the start of the group). Participants should also be offered a text or telephone reminder to attend sessions in order to improve attendance.

- Participants appeared to prefer the non-clinical setting of the group, therefore this should be maintained where possible.

- Consideration should be given to the weighting of what is recapped in sessions as this may impact on what is most likely to be taken away by participants after the end of the intervention. This will require further investigation in future evaluations.

4.3 Dissemination of Findings

Preliminary results of the group were fed back to the service in a presentation delivered during one of the weekly team meetings. It was also disseminated to other adult community learning disability services within the Trust through a cross-borough management meeting. These meetings include discussions on how services can manage waiting lists and the evaluation was presented in this context. Based on the outcome of the evaluation, the intention is to run the group again with the same format but with the amendments described above designed to improve uptake and attendance. The timing of this second group will be dictated by clinical need based on the size of the waiting list and length of wait for individual treatment.

Group interventions in learning disability services are a way of providing equivalent forms of treatment to non-learning disabled service users as recommended by the National Institute for Health and Clinical Excellence (2011) and fit with the stepped care model, which helps reduce the referral to treatment time. This evaluation suggests that such an intervention is acceptable to clients, inherently reduces referral to treatment time and perhaps provides a less

stigmatising and less clinical space for clients to receive psychological support. This evaluation sits within the 'practice-based evidence' sphere which Beail (2003) points out lacks the ability to contribute large scale, adequately powered research to the field. However, in the absence (or rather slow progression) of such research, practice-based evidence continues to provide valuable support to the use of psychological group interventions for people with learning disabilities. Further research is required to evaluate the efficacy of coping-based group interventions before they can be offered as a 'lower intensity' alternative to individual therapy.

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6. APPENDICES

Appendix 1 – Coping questionnaire:

Please note the measure was administered one question per page and not as displayed here.

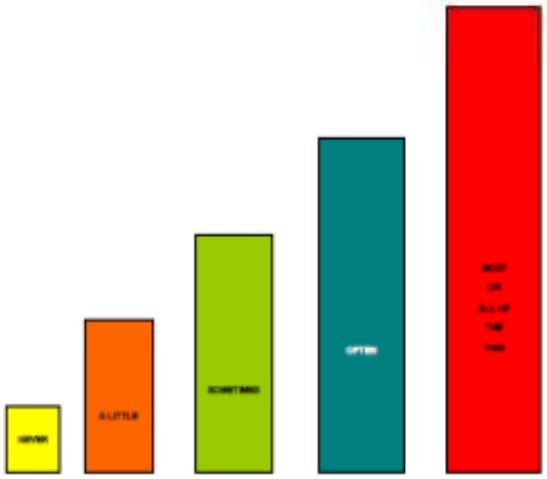
Name: Date:

Sometimes things can be difficult in your life. We would like to know what you do to help yourself when things are difficult.

We will show you some things people do to try to help themselves when things are difficult.

For each thing people do, please tick how often you do it. Please give an answer for every question.

People do lots of different things to help when things are difficult, so don't worry about what answer you give.



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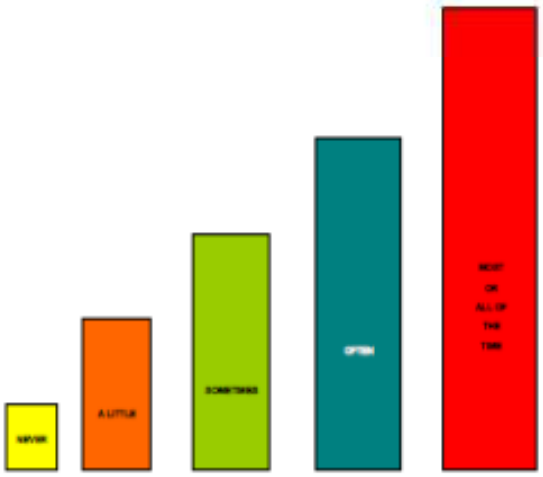

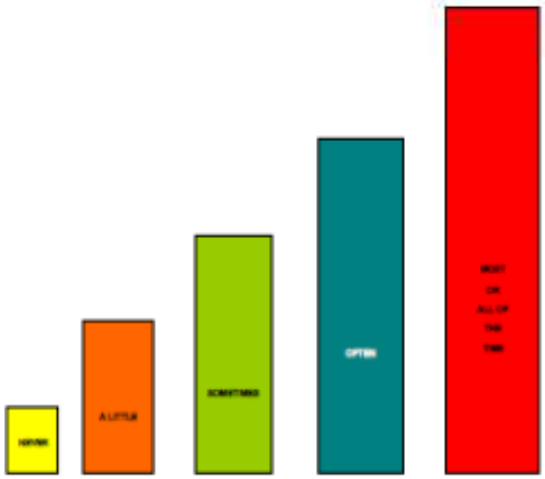

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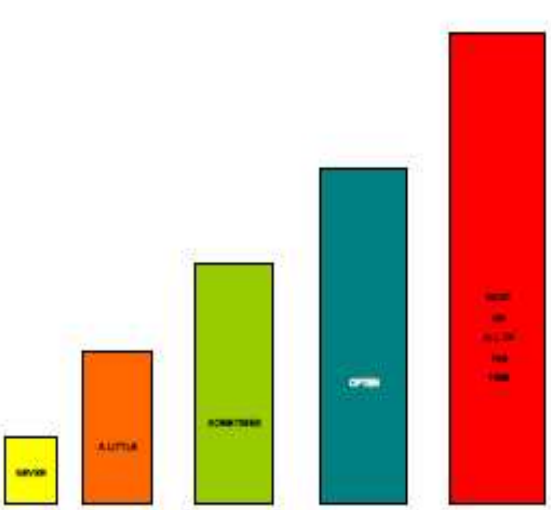
4

When things are difficult, I shout at people or say nasty things.

When things are difficult, I spend time with people who listen to me and care about me.



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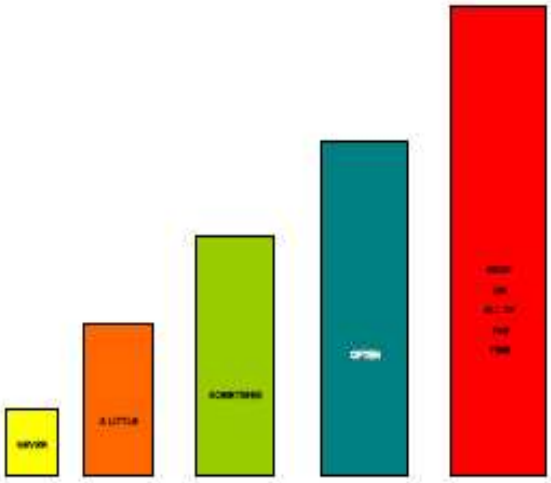

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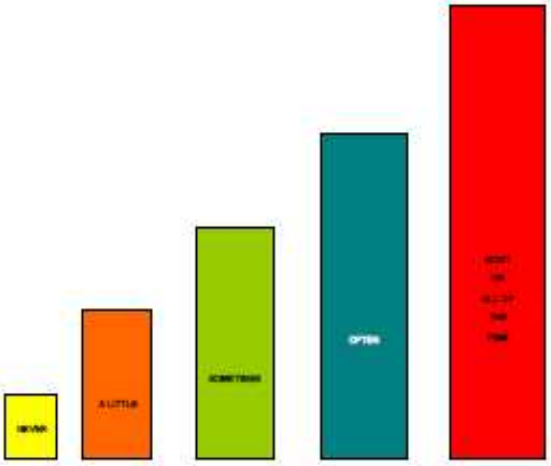
When things are difficult, I do exercise.

When things are difficult, I hide away from people or doing things.



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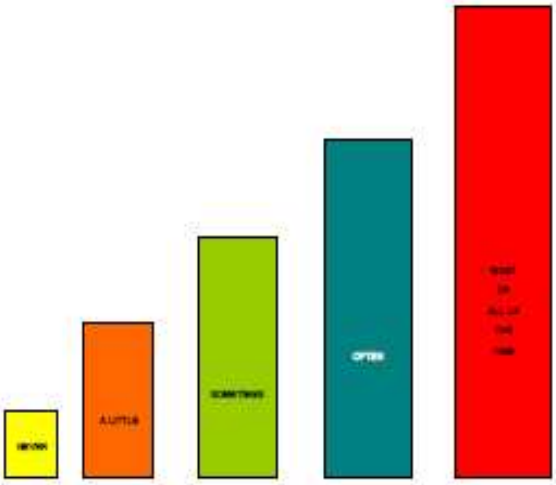
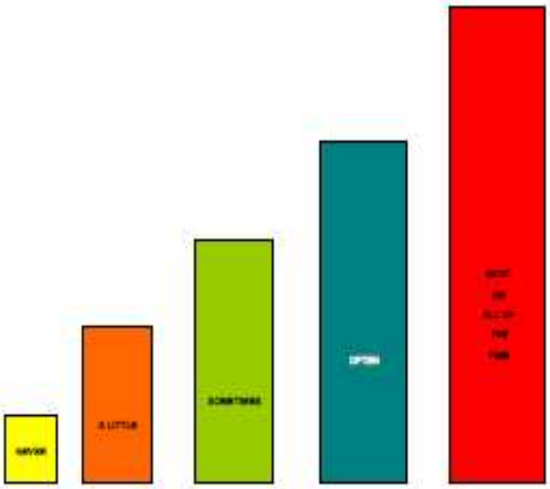
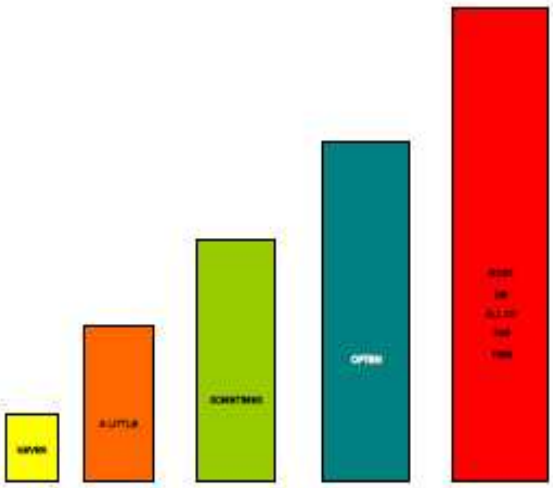


8

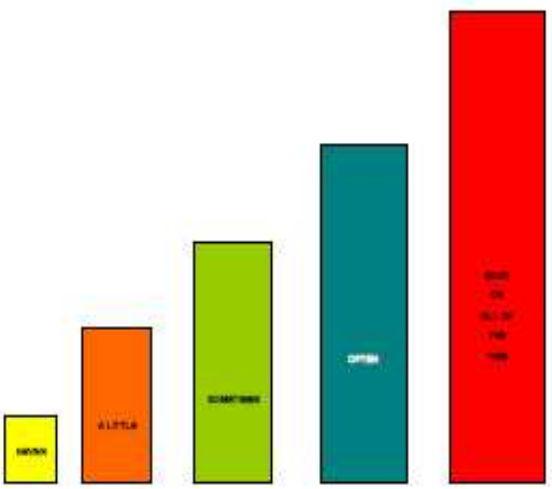
When things are difficult, I do my deep breathing exercises.



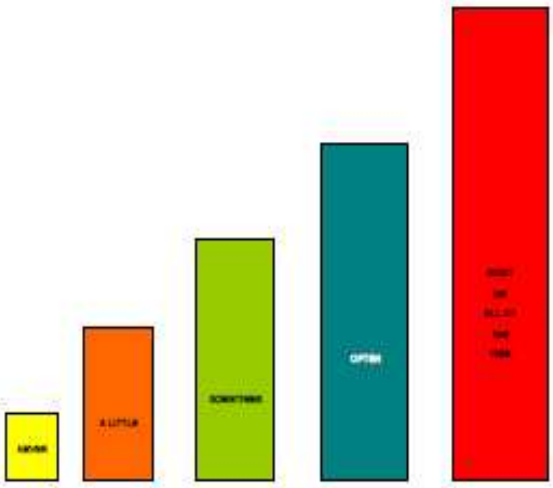
When things are difficult, I drink alcohol.



When things are difficult, I talk about what to do about my problems and make a plan.



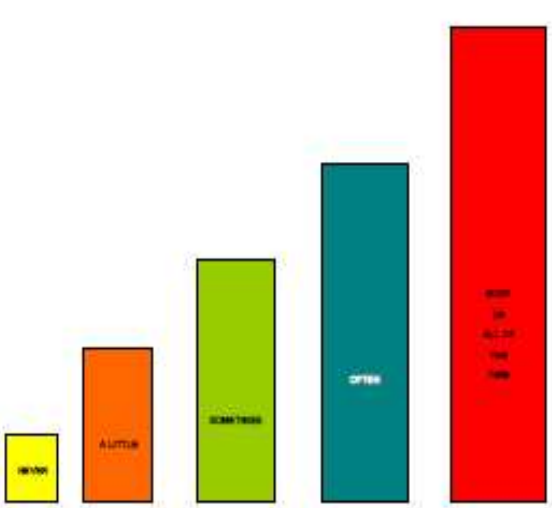
When things are difficult, I do my relaxation exercises.



When things are difficult, I take drugs.

13

When things are difficult, I try to think about the good things in my life.



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When things are difficult, I think it is my fault.

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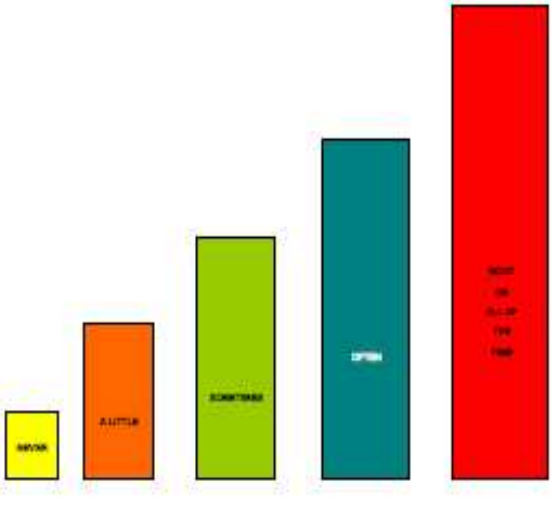
When things are difficult, I count until I feel better.



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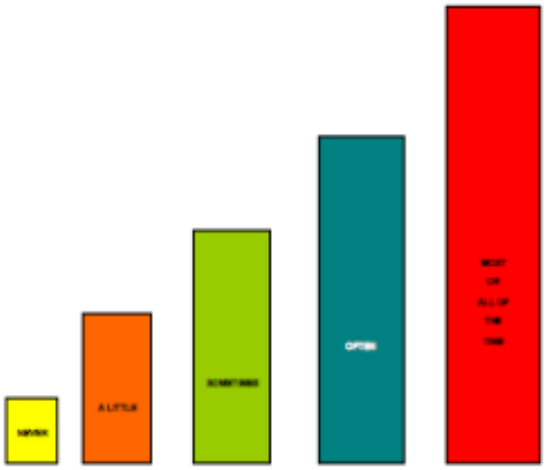

17

Main Research Project

Predictors of distress and coping in children with unusual experiences: the role of stigma and appraisal

Supervised by Dr Suzanne Jolley and Dr Sophie Browning

ABSTRACT

The apparent prevalence of psychotic-like experiences (PLEs) in children has prompted investigations into their prognostic significance and psychological factors which contribute to their development and maintenance. Recent research suggests psychological models of psychosis, which highlight the role of cognitive, social and emotional factors, may also be relevant to our understanding of PLEs. Primary and secondary appraisals of experiences have been implicated in symptom severity. In particular, stigma perceptions have been shown to impact on mood and quality of life and, in young people, stigma may pose an especially strong barrier to engagement with services. However the relationship between stigma, primary and secondary appraisals and PLE severity and distress has not previously been researched.

This study sought to investigate the relationship between primary and secondary appraisals, particularly stigma, and PLE severity and distress in a group of children and young people accessing secondary mental health services. Participants were recruited as part of a larger study trialling a cognitive therapy intervention for distressing PLEs. Participants completed questionnaires measuring PLE severity, distress, primary appraisals of the nature and cause of experiences and secondary appraisals of the implications of presenting problems.

Non-parametric correlations revealed a significant relationship between self-stigma and both PLE severity and distress and between problem perceptions and distress. The relationship between self-stigma and PLE severity was not accounted for by affect. A significant relationship was also observed between primary appraisals and distress. Trends towards significance were found in the relationships between self-stigma and personal stigmatising beliefs about mental health. No relationship was found between the stigmatisation of others and familiarity with mental health problems. The results partially support the application of cognitive models to PLEs; limitations of the study and its implications for PLE and stigma theory and for supporting young people with distressing PLEs are discussed.

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OVERVIEW

A focus of recent research interest has been the apparent prevalence of unusual or psychotic-like experiences (PLEs) in children. PLEs include phenomena such as hallucinations, ideas of reference and persecutory beliefs. Some argue for their prognostic significance, considering them to be a marker for increased risk of later mental health disorders, particularly psychosis. However, others assert that the high prevalence of PLEs (almost two thirds of children in some studies) means that the vast majority of PLEs cannot be pathognomonic and that either a qualitative distinction exists between clinical and non-clinical phenomena, or that PLEs are simply one of a number of vulnerability factors. These may not in themselves be pathological but may, in combination with other vulnerabilities (e.g. adverse life events or family history) or low mood, lead to increased likelihood of future mental health problems.

Up to a quarter of young people report current distress and life impact (i.e. an adverse effect on home or school life) associated with their PLEs. The new NICE guidance for psychosis in children and young people under 18 years recommends that, irrespective of their prognostic significance, PLEs accompanied by distress and/or impairment of functioning should be considered a target for psychological intervention in their own right. Understanding the psychological factors contributing to PLE severity and distress is therefore of particular importance for the development of such interventions.

Psychological models of psychosis highlight the cognitive, social and emotional factors contributing to the development and maintenance of psychosis. Very recent research suggests that similar factors may contribute to the severity of distress and impairment associated with PLEs. Central to such models of psychosis is the role of appraisal. Appraisals refer to primary interpretations of the nature of unusual experiences and secondary interpretations of their consequences. These are held to influence affective and behavioural reactions, and thereby to contribute to the development, severity, and persistence of symptoms.

Both primary appraisals of the nature and cause of experiences, and secondary appraisals of their implications and management have been associated with symptom severity. Secondary appraisals have also been shown to influence coping and engagement with treatment, across a range of health problems. In particular, perceptions of stigma, a core component of secondary appraisals, have been shown to influence treatment engagement in young people with mental health problems, and may therefore be particularly relevant for young people with PLEs.

The contribution of stigma and of secondary appraisals to PLE severity and distress in children has not previously been investigated. This study was designed to investigate these factors in a group of 8 to 14 year old children referred to Child & Adolescent Community Mental Health Services. As the area is unresearched, the first aim was to characterise this group of young people in terms of their views about mental health problems in general, their views of their own difficulties, and their views about PLEs. The second aim was to investigate the role of each of these factors in determining the severity of distress and impairment associated with PLEs. Finally, the inter-relationships between the different kinds of appraisals were considered.

In the literature review section of this thesis I shall first introduce the key concept of stigma and discuss how societal stigma is hypothesised to arise, with illustrative examples. I shall then discuss stigma towards people with mental health problems specifically and the pathway from societal stigma to internalisation of stigmatising beliefs and their application to the self. Internalisation of stigma is the primary mechanism by which stigma is hypothesised to impact on clinical outcomes in mental health. Particular emphasis will be placed on the small literature addressing how stigma can become internalised and how it may manifest in children in response to mental health problems. I will then discuss the concept of psychosis, cognitive models of the development of psychotic symptoms and how these relate to PLEs. I will elaborate on the role of appraisal in these models as the primary mechanism by which symptoms are hypothesised to develop and be maintained. I will discuss both primary appraisals of experiences and secondary appraisals of their implications, noting parallels with the stigma literature, and the nature of self-stigma as a secondary appraisal. Finally, I will consider how this can develop our understanding of distress and impairment associated with PLEs, and inform intervention approaches. I will propose a model of these associations, based on the existing literature (see section 1.3.2), which will generate testable hypotheses regarding the impact of stigma and other appraisals on PLE severity and distress, and regarding the development of self-stigma.

In Chapters 2 and 3 I shall describe the present study, including the development of measures through service user involvement, study procedure and statistical analyses. Finally, in Chapter 4, I shall discuss the interpretation of the results and their implication for theory, future research and supporting children and young people with distressing PLEs.

1. INTRODUCTION

1.1 Stigma

1.1.1 *Definitions and perspectives*

Stigma historically refers to a purposeful mark inflicted on a person to single them out as infamous or in some other way undesirable to society (Hinshaw, 2007; Stuart, 2008). While the use of a physical mark has declined, the process of singling a person out as part of an unfavoured group based on some characteristic remains and prevents full social acceptance (Goffman, 1963). In modern usage, stigma is usefully defined by Hinshaw (2007, p. 23) as the "global devaluation of certain individuals on the basis of some characteristic they possess, related to membership in a group that is disfavoured, devalued or disgraced by the general society." Stigma definitions vary across the literature (Crocker & Major, 1989; Goffman, 1963; Hinshaw, 2007; Jones et al., 1984) but common component processes include labelling, stereotyping, prejudice and discrimination (Corrigan & Watson, 2002; Link & Phelan, 2001).

The experience and impact of stigma has been documented for various groups including gay and lesbian communities (e.g. Herek & Capitanio, 1996), ethnic minorities (e.g. Tsuda, 1998), people with physical disabilities (e.g. Cahill & Eggleston, 1995) and those with mental health problems (e.g. Corrigan, Watson, Byrne & Davis, 2005). Goffman's (1963) comment on the impact of stigma highlights not only its consequences for the stigmatised but the tendency for it to pervade everyday interactions even if the labelling, stereotyping and discrimination is unintentional:

> "By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences. We use specific stigma terms, such as cripple, bastard, moron in our daily discourse, typically without giving thought to the original meaning." (p.15)

Goffman (1963) suggests that almost everyone is stigmatised at some point in their life; however Link and Phelan (2001) note that, while a multitude of differences exist between people, only some are stigmatised. They suggest that social power is critical in determining whether devaluation of one group by another develops into a stigma; for stigma to occur, the perpetrators must be in a position of power such that their labelling and denigration of the

stigmatised group has weight within the wider society. While the consequences of stigma are not universally negative (Cioffi, 2000; Crocker & Major, 1989; Crocker & Quinn, 2000; Miller & Major, 2000), the potential for adverse impact is great (Brohan & Thornicroft, 2010; Goffman, 1963; Hinshaw, 2007; Link & Phelan, 2001). Understanding how and why stigma develops and its impact on the stigmatised is central to reducing stigma and improving the life chances of stigmatised groups.

1.1.2 *Psychological models of stigma*

Stigma has been highlighted as a social process (Goffman, 1963; Major & O'Brien, 2005; Pescosolido, Martin, Lang & Olafsdottir, 2008; Stuart, Arboleda-Florez & Sartorius, 2012, p.6), therefore psychological contributions to stigma theory have largely been informed by social psychological approaches (Corrigan and Watson, 2002; Link and Phelan, 2001; Ottati, Bodenhausen & Newman, 2005), drawing on concepts including attribution theory (Weiner, 1993) and social identity theory (Tajfel & Turner, 1986). Models of stigma have tended to focus on the processes involved in the development of stigma. Maintenance factors and associated psychological processes, such as information processing biases, have been described in non-mental health stigma (e.g. Hamilton & Rose, 1980; Vargas, Sekaquaptewa & von Hippel, 2004) but so far little research is forthcoming in the field of mental health (Boysen & Vogel, 2008).

The leading psychological model, also called the socio-cognitive model, in the existing literature is that of Corrigan (2000), who in conjunction with Link and Phelan (2001) identified key processes which appear to be common across stigma settings. These are: labelling, stereotyping, prejudice and discrimination (Corrigan, 2000; Link & Phelan, 2001). The last three are interlinked, but separate, components of the stigmatisation process. Stereotyping involves applying negative attributes to a labelled group; prejudice is the endorsement of that belief, usually accompanied by a negative emotional reaction (e.g. fear or anger); discrimination describes the behavioural response to prejudice (e.g. rejection or exclusion) that distinguishes a stigmatised group from non-stigmatised groups (Corrigan & Watson, 2002). Link and Phelan (2001) add status loss to the discrimination process, emphasising the difference in social power which occurs in their model of societal stigma. One example of the stigmatisation process in action is the propaganda campaign by the Nazi party against the Jewish community in the 1930s. Posters, cartoons and newspaper reports repeatedly sought to establish a stereotype of Jewish people as wealthy, powerful and opposed to the progression of Germany (Loewenberg, 1987). The establishment, or reinforcement, of the stereotype was designed to create prejudice against the Jewish communities, such as anger at the perceived power and wealth of Jewish people. Discrimination began with the boycotting of Jewish shops and

culminated in *Krystallnacht*, the destruction of Jewish businesses, homes and synagogues which preceded the Holocaust. Although the stigmatising of a group in this instance was manufactured by a political power, it exemplifies the process by which a group can become stigmatised. Stereotypes begin to shape, or even alter, beliefs about the 'to be stigmatised' group and these beliefs subsequently affect the way in which people respond to that group. The endorsement of stereotypes, emotional responses and behavioural reactions to a group are therefore all important in understanding stigma and its effects.

Hinshaw's (2007) definition implies that the stigmatisation occurs in two stages. First, a group or section of society is labelled as "disfavoured, devalued, or disgraced" (p.23). This may occur through stereotyping, which can be based on past experience, information in the media or learned from others (Corrigan, Powell & Michaels, 2013; Wahl, 2002). Second, a person is identified as part of that group by way of some 'marker' (a visible identifier) which has become associated with the negative preconceptions about that group (Sartorius & Schulze, 2005). Having been identified as a member of the devalued group, the subsequent behaviour towards the stigmatised person will be driven by expectations based on the perceived characteristics of the group to which the person has been assigned. From a sociological perspective, Goffman (1963, p.12) usefully referred to this as the "virtual social identity" which may differ from the "actual social identity". That is, the initial assumptions being made about the other person are based on a set of assumed characteristics and not on their actual characteristics; indeed a person may expect certain behaviour from a stigmatised group without ever having personally witnessed that behaviour themselves (Hinshaw, 2007). Goffman (1963) points out that this rapid categorising of others is often useful as it allows us to respond quickly in social situations to new people. However, it can result in the creation of categories in which people are perceived as inferior to the point of being viewed as "not quite human" (p.15), which leads to discrimination and reduced opportunities and hence quality of life for the stigmatised person.

1.1.3 *Societal stigma and mental health*

The stigma surrounding mental health can be traced back through history and an informative account is given by Hinshaw (2007). In ancient Greece and Rome, reactions to mental health problems varied from treatment based on rest, exercise and healthy living to persecution and murder. However, whether persecuted or pitied, the dominant response was still to view people with mental health problems as separate from the rest of society. Institutionalisation began around the ninth century, sometimes with the genuine motivation of treatment and care (Henry, 1941) but often resulting in isolation and confinement (Hinshaw, 2007, p. 60). The asylums which followed were all too often unsuitable or inhumane. The reaction to children

with mental health problems has followed a similar trajectory, with orphanages being the principle institutions of care until the nineteenth century (Hinshaw, 2007).

Research into stigma in mental health has focused both on the societal stigma of mental health problems and on the internalisation of this stigma for those experiencing mental health problems (Brohan & Thornicroft, 2010; Young Minds, 2010). *Societal stigma*, as the name suggests, refers to society's stigmatisation of people with mental health problems. There may be a difference between the level of societal stigma present and the level perceived by an individual with mental health problems, for example if they themselves are unaware of being labelled as 'mentally ill' (Mak & Wu, 2006). The extent to which people hold stigmatising beliefs about others (SO) may also vary according to the disorder; for example, research comparing labels of psychosis and Schizophrenia to labels of other mental health problems such as depression, anxiety disorders and dementia have shown that SO appears to be greater in response to psychosis than other mental health problems. In particular, people with psychosis are more likely to be viewed as dangerous and unpredictable than people with depression, anxiety disorders or dementia (Angermeyer & Dietrich, 2006; Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Jorm, Reavley & Ross, 2012; Yap, Reavley, Mackinnon & Jorm, 2013). This would indicate that people with psychosis may be particularly vulnerable to stigma.

Recent evidence points to a modest improvement in mental health stigma in response to public health education and stigma reduction campaigns; however there is further progress yet to be made in understanding the impact of familiarity, education and contact on stigma (Corker et al., 2013; Evans-Lacko, Henderson & Thornicroft, 2013; Henderson, Williams, Little & Thornicroft, 2013; Thornicroft et al., 2013). Alonso and colleagues (2008) found that, for anxiety and depression alone, SO was more strongly associated with mental health problems than chronic, non-infectious physical health problems. SO around mental health problems has been found to be associated with poorer quality of life and psychological distress in those being stigmatised (Markowitz, 1998; Rosenfield, 1997). There are also more practical consequences of SO; Sharac and colleagues (2010) found an adverse effect of mental health stigma on employment, income and public funding for support based on 27 studies in 10 countries over 50 years.

The stigma and prejudice against mental health is also, unfortunately, not limited to the lay public. It has been suggested that mental health service users also face stigma from the services they access through lack of communication and inclusion (Sartorius & Schulze, 2005), being identified as a 'high-stress' group to work with (Sartorius, 2002) and services' use of

language to describe service users (Flanagan, Miller & Davidson, 2009). This institutional stigma may slow the reduction in, or even maintain, societal stigma. Societal stigma which is perceived by those seeking help as reinforced by services may therefore deter people (particularly young people) from accessing such services and may contribute to self-stigma.

1.1.4 *Internalised mental health stigma*

Self-stigma, or self-stigma (SS), refers to the process whereby a person becomes aware of and in some way endorses the societal stigma attached to a particular group. If they then identify themselves as a member of that group, they will internalise the societal stigma and 'self-stigmatise' (Corrigan & Rao, 2012; Corrigan & Watson, 2002; Goffman, 1963; Hinshaw, 2007; Watson, Corrigan, Larson & Sells, 2007). This is argued to be when the stigma of mental health problems is most damaging (Green, Hayes, Dickinson, Whittaker & Gilheany, 2003) and self-stigma has been associated with poorer self-esteem, reduced empowerment and even symptom severity (for a review, see Livingston & Boyd, 2010). The extent to which people self-stigmatise varies according to affect and external factors (Ben-Zeev, Frounfelker, Morris & Corrigan, 2012).

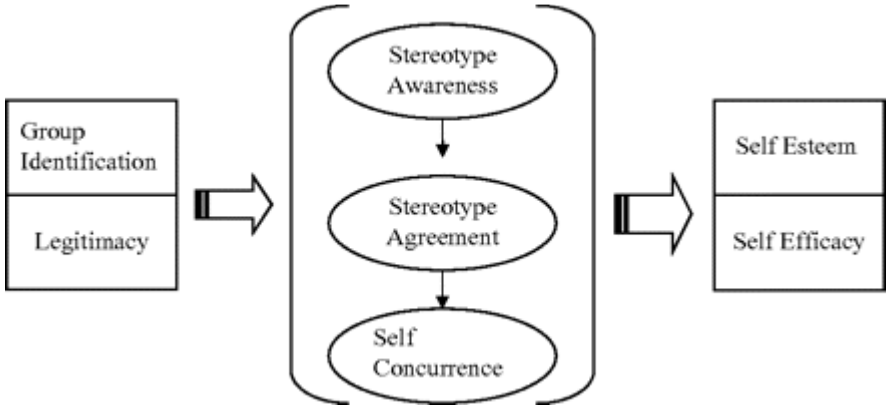

Figure 1.1: Model of self-stigma (from Watson et al., 2007)

If, as Corrigan and Watson (2002) suggest, some endorsement of societal stigma is necessary for the development of self-stigma, it may be the case that a person's perceptions of their own mental health problems (i.e. the extent to which they self-stigmatise) is influenced by the level to which they endorse societal stigma. An association should therefore be observable between stigmatising attitudes towards mental health (SO) and the level of self-stigma in people with problems which could lead them to be labelled as 'mentally ill' (the stigmatisation of oneself, SS). Preliminary research has found such associations in adults (Watson et al., 2007). However this research used stereotype agreement as the sole measure of SO, which is not a comprehensive assessment. The researchers also incorporated the SO item into the SS

measure, which may have led to an increased influence of SS on responding and artificially increased the association, rather than measuring the concepts separately.

Corrigan and Watson (2002) suggest that the awareness of societal stigma and agreement with the stereotypes of mental health problems is necessary but not sufficient for this stigma to become internalised. They suggest that the perceived legitimacy of the societal stigma is another key component. If the individual perceives as legitimate the societal behaviours resulting from the stigma, then they may be more prone to self-stigmatise. If, on the other hand, societal behaviours are perceived as illegitimate (i.e. unjust) then they may respond either with "righteous anger" (p.40) if they identify themselves as part of the stigmatised group, or with indifference if they do not.

Civil rights movements are exemplars of stigmatised groups responding with righteous anger. For example, Rosa Parks, the civil rights campaigner who defied a segregation law by refusing to give up her bus seat for a white passenger, recognised the stigma and discrimination levelled against her due to her ethnicity. She perceived this as illegitimate and so refused to endorse the belief that black people were inferior by giving up her seat (Parks & Haskins, 1992). Righteous anger could be considered to be part of stigma resistance, the process of counteracting or resisting societal stigma, which has only recently been explicitly addressed in studies of responses to mental health stigma (Sibitz, Unger, Woppmann, Zidek & Amering, 2009). The findings that stigma resistance is negatively correlated with alienation, stereotype endorsement and social withdrawal but has no association with discrimination experience (Sibitz et al., 2009) supports this assertion in that the extent to which prejudice and discrimination is perceived as illegitimate need not be affected by experience of actual discrimination.

There are also occasions when people with mental health problems reject the societal label and consequently do not self-stigmatise (Camp, Finlay & Lyons, 2002), although it remains unclear whether the underlying mechanism is perceiving the stigma as unjust or simply not identifying themselves as part of the group to which the stigma is applied. There are examples of groups who not only do not necessarily view psychosis as pathological but as meaningful or even positive experiences, such as the Hearing Voices movement (Escher & Romme, 2012). Research has suggested both that mental health diagnoses (including psychosis and affective disorders) have been evident in eminent creative figures and that people with psychosis have scored higher compared to controls on measures of divergent thinking, which is associated with creativity (Keefe & Magaro, 1980; Ludwig, 1995). Claridge and Blakey (2009) found that

positive schizotypy, in particular unusual experiences, were associated with self-perceptions of creativity though not divergent thinking and Schuldberg (2001) found a relationship between positive symptoms of schizotypy and creativity, though this concept was not readily separable from hypomania, which was found to be most associated to creativity. It may be the case that such positive appraisals of unusual experiences (i.e. as meaningful or positive experiences) may reduce the tendency to self-stigmatise or the distress caused by such experiences. It is suggested that groups such as the Hearing Voices Network (www.hearing-voices.org) may help to destigmatise such experiences through this process (Kendall & Rogers, 2007).

1.1.5 *The impact of familiarity on the stigmatisation of others (SO)*

As Goffman (1963) and Hinshaw (2007) both state, stigmatising assumptions about others can be formed without having had contact with the stigmatised group. A number of studies have therefore investigated how contact with people with mental health problems affects SO. A common finding is that education and contact with people with mental health problems tend to be associated with reduced SO (Bellanca & Pote, In Press; Corrigan, Edwards, Green, Diwan & Penn, 2001; Couture & Penn, 2003; Evans-Lacko, Malcolm et al., 2013; Jorm et al., 2012; Pinfold et al., 2003; Pinfold, Thornicroft, Huxley & Farmer, 2005; Sartorius & Schulze, 2005).

To use Goffman's (1963) concepts of the virtual and actual social identity, one possible mechanism for this effect is that contact with a person from a stigmatised group increases the opportunity to observe their actual social identity (that is, their real characteristics), which contradicts the virtual social identity (their assumed characteristics). This creates a kind of cognitive dissonance between the virtual and actual social identities, leading to a correction of the virtual social identity in the observer. However, it is reported that contact should occur under specific conditions as it has occasionally been associated with increases in SO (e.g. Corrigan et al., 2005). It is suggested that contact which is voluntary, in which the person with mental health problems has equal status to the participants, and where the person with mental health problems mildly contradicts stereotypes is most likely to reduce stigma (Corrigan, River et al., 2001; Couture & Penn, 2003). The equal status of the participants may be explained by the shift in social power created (Link & Phelan, 2001), such that the stigmatising attitudes of the observers no longer carry weight as they do not have social power over the stigmatised person. The need for the person with mental health problems to mildly contradict stereotypes is necessary to avoid reinforcing stereotyped beliefs about mental health. It is also suggested that, if the person too radically contradicts the stereotype, the person themselves might be 're-categorised' as not being a member of the stigmatised group rather than the virtual social identity of the group itself being corrected in the observer.

1.1.6 *Stigmatising beliefs in young people*

The stigmatisation of mental health problems in and by young people has received increased attention over the last decade. Since it is during childhood that social cognition develops (Flavell, Miller & Miller, 1993), this would suggest that attitudes towards mental health and experience of stigma in childhood are important for understanding stigma and its impact later in life. Childhood is also a critical period for the development of self-concept (Marsh, 1990; Rosenberg, 1979) and by adolescence children are able to quickly identify with ingroups and form prejudices and discriminate against outgroups, as demonstrated by the Robbers Cave experiment (Sherif, Harvey, White, Hood & Sherif, 1961). In this study, 12 year old children were placed in two groups based on similarities. They were then put in competition with each other, which is when prejudices and discrimination were observed. When the groups were integrated so they had to work together to achieve a goal, these prejudices were noted to reduce. This kind of study has implications not only for how young people view mental health problems but how they appraise mental health problems within themselves.

Mukolo, Keflinger and Wallston (2010) and Hinshaw (2005) suggest that models of mental health stigma in young people need to take into account stigma processes for the family and institutions (such as school) to a greater extent than in adults. They therefore question the generalisability of stigma research in adults to child and adolescent populations. For example, it suggested that there is a tendency for younger children to be less stigmatised in terms of blame or responsibility for their problems due to their young age; however, this potentially results in the blame or responsibility which would be attributed to the child being applied to the parent instead (Mukolo et al., 2010; Hinshaw, 2005). As the child ages, it is suggested that the distinction between the person and the mental health problem becomes blurred and stigmatisation of the young person becomes more likely. In spite of these suggested distinctions, it appears the prevailing view in the literature is that models of the formation of stigma described above are as relevant to the development of stigma in young people as they are in adults (Fox, Buchanan-Barrow & Barrett, 2008; Mukolo et al., 2010), even though the sources of information on which stigmatising beliefs are built may be different.

Early work by Thomas Scheff (1963) suggested that stereotyped views of mental illness are developed in early childhood and reinforced by social interactions and mass media (for example in press or in the way people with mental health problems are portrayed on fictional television shows). Some researchers have suggested that these views were relatively stable by the age of five to six years and changed little as the child grew up (Weiss, 1986, 1994). Other

studies, however, have found that children's conceptions of mental health problems are not well formed, and that their understanding becomes more sophisticated over time (Adler & Wahl, 1998; Fox et al., 2008). Nonetheless, Adler and Wahl (1998) noted that children still held more negative beliefs about adults labelled 'mentally ill' than about physically ill adults or those without any disability. More recently, children's views of mental health problems have been found to reflect parental views (Jorm & Wright, 2008) and to some extent stories in the media (Morgan & Jorm, 2009; Wahl, 2002).

Stigmatising behaviour towards peers is also evident in children. In terms of their responses to mental health problems, research has compared children's behaviour towards peers when they did or did not believe them to have a mental health diagnosis. This research found that children responded more negatively to those who they believed to have mental health problems (even if they were a stooge) than those without such a label (Gillmore & Farina, 2008; Harris, Milich, Corbitt, Hoover & Brady, 1992).

It has been suggested that young people are more likely to be the recipients of SO than adults (Rose, Thornicroft, Pinfold & Kassam, 2007). However, less work has been done to distinguish the impact of experienced societal stigma from the internalisation of stigma, and evidence for the impact of stigma on children and young people with mental health problems is also lacking (Penn & Wykes, 2003). However preliminary evidence suggests that the experience of societal stigma is associated with lower self-esteem, greater SS and higher depression scores (Moses, 2009).

The majority of research on the impact of stigma to date has focussed on behavioural consequences such as help-seeking and suggests that stigma (whether SS or the expectation of SO from others) is a key barrier to young people accessing services in times of mental health difficulties, which implies avoidance of disclosure and an association of stigma with poorer current functioning and longer term outcomes (Burns, Durkin & Nicholas, 2009; Chandra & Minkovitz, 2007; Gulliver, Griffiths & Christensen, 2010; Heflinger & Hinshaw, 2010). Further to this, studies of adult and adolescent help-seeking for mental health problems suggest that stigma may represent a more important barrier to seeking help for young people than for adults (Gulliver et al., 2010; Mojtabai, 2010; Mojtabai et al., 2011). The reason for this is unclear, though it is suggested that reluctance to seek-help in young people may relate to feared social reaction from their peers (Rickwood, Deane, Wilson & Ciarrochi, 2005). It is also important to consider parental influences on mental health service use in children and adolescents, since parents may play an important role in this (Logan & King, 2001; Rickwood et

al., 2005). Research has suggested that parental perceptions of mental health services may influence service use (Logan & King, 2001) or that parental disapproval acts as a barrier to help-seeking in young people (Chandra and Minkovitz, 2006). However, specific stigmatising parental perceptions of mental health and their impact on help-seeking in young people has not been well researched, with a small study finding no significant relationship between parental perceived stigma and help-seeking (Czuchta & McCay, 2001).

While some research has found SO to be a common reaction to the identification and labelling of mental health problems (Bailey, 1999; Corrigan et al., 2005; Wahl, 2002; Yap & Jorm, 2011), other studies have suggested that accurate labelling of mental health problems is associated with effective help-seeking and this outweighs the risk of SO from the public (Wright, Jorm & Mackinnon, 2012; Yap et al., 2013). Within young people, as in adults, the nature of the mental health problem may influence the processes involved: a label of psychosis appears to increase vulnerability to experiencing SO from others and such a label was found to increase perceived dangerousness in participants (Yap et al., 2013). Self-stigma in young people and its formation is relatively under researched and Mukolo and colleagues (2010) state that more study is needed to understand when in childhood self-stigma begins to develop. Understanding the influences on, and impact of, stigma and how or when it becomes internalised is therefore important to guiding interventions which can reduce stigma and thereby improve help-seeking.

1.2 Psychotic-Like Experiences (PLEs)

1.2.1 *Cognitive models of psychosis*

Over the last twenty years, cognitive models incorporating biopsychosocial vulnerabilities and cognitive and emotional processes have been increasingly applied to the understanding of psychosis (Bentall, Fernyhough, Morrison, Lewis & Corcoran, 2007; Chadwick & Birchwood, 1994; Garety, Kuipers, Fowler, Freeman & Bebbington, 2001; Hemsley, 1993; Morrison, 2001). Such models demonstrate a shift in focus from the mere presence of psychotic symptoms to the emotional, cognitive and behavioural drivers of and responses to such experiences. According to these models, anomalous or unusual experiences occur in the context of a particular trigger (such as a period of increased stress) for people with a biopsychosocial vulnerability to such experiences. Once the experience occurs, cognitive models emphasise the importance of the interpretation of the experience, which is informed by pre-existing belief structures and reasoning patterns. It is the interpretation of experiences which is hypothesised to be primary in both the onset and maintenance of psychotic symptoms. Appraisals of experiences are therefore central to cognitive models and are suggested to be a major factor

in the progression from unusual perceptual experiences to clinical psychosis (Lovatt, Mason, Brett & Peters, 2010; Peters, Williams, Cooke & Kuipers, 2012; Peters, Lataster et al., 2012)

1.2.2 *Continuum models of psychotic experiences*

Cognitive models of psychosis have developed in tandem with a paradigm shift in the conceptualisation of Schizophrenia from being a discrete disorder to one existing on a continuum of a psychosis 'phenotype', which includes sub-clinical psychotic symptoms and 'unusual' experiences not reaching the criteria for psychotic symptoms (Chapman & Chapman, 1980; Strauss, 1969). This has been prompted in part by observations that experiences usually subsumed under the symptom profiles of psychotic disorders have been observed within the general population without diagnoses or even the need for treatment (Kelleher & Cannon, 2011; Nelson, Fusar-Poli & Yung, 2012; Strauss, 1969; van Os, Hanssen, Bijl & Ravelli, 2000; Yung et al., 2006). Cognitive models of psychosis drew on this literature to suggest that unusual experiences can occur without the interpretative processes which lead to the development of a psychotic disorder and therefore such experiences should be conceptualised as existing on a continuum.

The presence of these experiences (for example, hallucinations) in the absence of a diagnosable disorder has led them to be termed 'psychotic-like experiences' (PLEs). This term recognises the similarity of PLEs to symptoms of psychosis while distinguishing them as essentially non-clinical phenomena. PLEs could be classed in cognitive models as a vulnerability factor which only forms part of a psychotic disorder when interpreted in a way which increases and maintains distress. PLEs have been shown to be common in various populations around the world (Fonseca-Pedrero et al., 2011; Leiderman, 2011; Ndetei et al., 2012; Nuevo et al., 2012; Scott et al., 2008; Sharifi et al., 2012). Understanding PLEs as existing on the same continuum as clinical psychosis implies that studying them has great potential to improve our understanding of the factors predicting vulnerability to psychosis. Researchers have therefore sought to investigate the processes that influence the severity of PLEs (their varying degrees of persistence, associated distress and impact), which of these factors are common to both PLEs and psychosis, and what distinguishes the experience of non-clinical PLEs from the experience of clinical psychosis (Nelson et al., 2012; Scott, Chant, Andrews & McGrath, 2006).

While continuum perspectives have gained support, some have argued against the assumption that clinical and non-clinical phenomena share aetiological and maintaining processes and debate the utility of a PLE concept. Lawrie, Hall, McIntosh, Owens and Johnstone (2010) acknowledge the presence of psychotic symptoms in non-clinical populations and the

questionable validity of categorical diagnostic systems. However, they argue that it does not necessarily follow from the observed phenomenological similarity that PLEs in clinical disorders are underpinned by the same psychological mechanisms as non-clinical PLEs. David (2010) issues a similar warning, arguing that continuum models have many benefits but that even when considering a continuum, a categorical cut-off is usually applied to identify different groups. He also suggests that the methods by which experiences are elicited will affect how frequently they are reported. Horwood and colleagues (2008) found that PLEs were less prevalent when measured using a semi-structured interview than when measured using a self-report questionnaire, though PLEs were still relatively common (13.7%) even when measured by interview. Sommer (2010) argues that, even though a continuum of experiences is observed in terms of the endorsement of experiences, there may still be differences in the quality of experiences between those with and without clinical disorders, which requires further study. Preti, Cella, Raballo and Vellante (2012) propose a pyramid model for risk of psychosis whereby PLEs are separated into two categories based on appraisals and distress and are categorised separately from sub-threshold psychotic symptoms and diagnosed psychosis. Kaymaz and van Os (2010), however, suggest that the distribution of psychotic experiences across the population is indicative of an 'extended phenotype'. They recommend that more research studies involving people with psychotic experiences with and without the need for care are undertaken, in order to clarify whether PLEs and psychotic symptoms exist on a full continuum or are overlapping but categorically distinct experiences.

For the purposes of the present study, PLEs are conceptualised as existing on a phenomenological and mechanistic continuum in accordance with cognitive models. This is because the focus of this study is on the psychological factors contributing to PLEs and how these are appraised.

1.2.3 *PLEs in young people: prevalence and associated mental health risk*

PLEs have been found to be more common in child populations than in adults (Laurens, Hobbs, Sunderland, Green & Mould, 2012; Poulton, 2000; van Os, Hanssen, Bijl & Vollebergh, 2001; Yung et al., 2009). Prevalence rates for PLEs in children in the general population vary widely, ranging from seventeen percent to almost two-thirds of children aged nine to twelve years (Kelleher et al., 2012a; Laurens et al., 2012). The variation in prevalence estimates can mainly be accounted for by the number and types of PLEs investigated and the definition of a PLE. For example, some studies use PLE synonymously with sub-clinical psychotic symptoms (Kelleher et al., 2012b) elicited by interview. Within such studies, PLEs might be considered to be fundamentally 'different' to normal childhood experiences due to the focus on psychotic

symptoms not reaching the threshold for clinical diagnosis. Other research has used a more inclusive definition which encompasses a wider range of unusual experiences, such as thoughts of being controlled, mind reading, thoughts of having special powers or magical thinking, assessed psychometrically (Laurens et al., 2007). These methods conceptualise PLEs on a continuum of normality rather than pathology, with many of the experiences common in children and young people, but still sharing some of the same interpretative processes which may cause distress or increase risk of later mental health problems. In spite of the varied prevalence findings being potentially accounted for by measurement methods, the prevalence of PLEs in children aged nine to twelve years is noted to be greater than that in young people aged thirteen to eighteen years (Kelleher et al., 2012a), which is greater still than that in adults (van Os, Linscott, Myin-Germeys, Delespaul & Krabbendam, 2009). It therefore appears that, for many, PLEs are transitory and resolve over time (De Loore et al., 2011; Linscott & van Os, 2013; Thapar et al., 2012).

For a minority of children and young people, however, PLEs may persist and may represent a difficulty worthy of intervention in their own right as well as a potential risk factor for the later development of an at-risk mental state (De Loore et al., 2011; Dominguez, Wichers, Lieb, Wittchen & van Os, 2011; Kelleher & Cannon, 2011; Nelson et al., 2012; Welham et al., 2009) or other psychological and behavioural problems (Downs, Cullen, Barragan & Laurens, 2013; Mackie, Castellanos-Ryan & Conrod, 2011; Nishida et al., 2008). Laurens, Hodgins, Taylor, & Murray (2011) found that over a third of children with PLEs reported either distress or functional impairment (that is, the experience causes difficulties for the child at home or at school) relating to these experiences and twelve percent reported both. Numerous studies have also found PLEs to be associated with current psychological distress (Barragan, Laurens, Navarro & Obiols, 2011; Kline et al., 2012; Varghese et al., 2011), poorer health status (Nuevo et al., 2012), peer problems (Campbell & Morrison, 2007; Kelleher, Murphy & Cannon, 2010) and behavioural problems (Kinoshita et al., 2011; Nederlof, Muris & Hovens, 2012; Nishida et al., 2010). While these studies are typically cross-sectional and cannot demonstrate causal relationships, they suggest that young people with severe or distressing PLEs are likely to have needs which may benefit from intervention.

Investigation of the trajectories of PLEs led Nelson and Yung (2009) to suggest that there are distinct presentations of young people with PLEs: i) PLEs as part of an underlying disturbance; ii) PLEs as epiphenomenal to other problems for which a person might seek help, such as anxiety or depression; or, iii) PLEs present in people with no clinical problems and conferring no increased vulnerability. However, while it is evident that people with PLEs could be grouped

into those with or without distress or other problems, completely separate classifications of PLEs in this way could be construed as moving back towards a categorical conceptualisation of psychotic experiences where those experiences which are accompanied by distress are fundamentally different to those which appear more 'benign'. Research has suggested that certain subtypes of PLE (e.g. bizarre experiences and perceptual abnormalities) may confer higher risk for distress or development of clinical psychosis than others (Armando et al., 2010; Yung et al., 2006). Others have argued, more in keeping with cognitive models of psychosis development, that it is factors such as the persistence of the experiences, distress and poor coping which particularly predict psychosis onset rather than the type of PLE (Lin et al., 2011; Linscott & van Os, in press; Wigman et al., 2011), although the severity of the experiences is still important (Bak et al., 2003). Moreover, emerging research suggests that similar cognitive, social, emotional and behavioural factors to those implicated in the development and maintenance of adult psychosis may drive PLE persistence and severity (Arseneault et al., 2011; Fisher et al., in press; Kelleher et al., 2008; Morgan et al., 2009), and that cognitive therapy has potential as a means of reducing distress in young people with distressing PLEs (Maddox et al., 2013).

1.2.4 *The role of appraisals of experiences*

Appraisals of experiences are core to the cognitive model of the development and maintenance of positive symptoms of psychosis (Garety et al., 2001). It is argued that it is the interpretation of anomalous experiences, and not the experiences themselves, which would be expected to determine the degree of associated distress and impact, the person's ability to cope and, ultimately, distinguish between the development of non-psychotic and psychotic presentations. Both primary appraisals of the nature and cause of an experience, and secondary appraisals of its implications and manageability have been implicated in the maintenance of psychotic symptoms.

Primary appraisals

Interpretations of unusual experiences as being externally caused, or external in origin, personal, and threatening (e.g. "someone else is targeting me because they mean me harm"), are suggested to increase the likelihood of psychosis developing or a 'need for care' (Garety et al., 2001; Lovatt et al., 2010). Conversely, making a more adaptive and normalising appraisal, (e.g. attributing the PLE to stress) is hypothesised to have a potentially protective effect which will reduce the risk of psychosis. In support of this, appraisals of unusual experiences have been found to discriminate between clinical psychosis and non-clinical groups, with a clinical group characterised by more external, personal and threatening interpretations of

experiences, which were in turn associated with increased distress (Brett et al., 2007; Lovatt, Mason, Brett & Peters, 2010). Appraisals have also been found to influence the course of voice hearing in a group of young people in or out of treatment (Escher, Romme, Buiks, Delespaul & Van Os, 2002). No study to date has explicitly considered the associations between self-stigma and primary appraisals of experiences. However, it is clear in adult research that normalising appraisals are adaptive in terms of PLE severity, and that stigmatising beliefs about mental health are not predicated on normalising and accepting attitudes towards unusual experiences (Lovatt et al., 2010). It is hypothesised that stigmatising beliefs may bias the person away from neutral and adaptive explanations and towards external and threatening explanations, as an internal attribution would carry significant adverse consequences.

Secondary appraisals

In addition to primary appraisals of the meaning of experiences, secondary appraisals of their consequences are also of interest in studying PLEs. Secondary appraisals of illness have been shown to influence outcomes across multiple physical health as well as mental health problems. Leventhal (1970; Leventhal, Diefenbach & Leventhal, 1992) suggested that individuals manage health 'threats' based on their representations of the illness. These representations are split into objective representations of the threat itself and subjective representations of their emotional response. The different representations are hypothesised to influence coping responses and appraisals, and thereby the management of the health threat and emotional response, and together form a self-regulatory system. The five representations proposed by this model (Leventhal et al., 1997) – identity, consequences, timeline, control and cause – have been extended over time to include illness coherence, emotional representations and timeline perceptions for cyclical problems (Moss-Morris et al., 2002). The self-regulatory model has been commonly used in research on treatment adherence (Cooper, Lloyd, Weinman & Jackson, 1999; Horne & Weinman, 2002; O'Connor, Jardine & Millar, 2008; Ross, Walker & MacLeod, 2004) but beliefs about physical illness have also been associated with outcomes such as coping (Moss-Morris, Petrie & Weinman, 1996; Scharloo et al., 2000; Zyrianova, Kelly, Sheehan, McCarthy & Dinan, 2011), distress (Dempster et al., 2011; Fischer et al., 2012) and illness outcome (Cartwright, Endean & Porter, 2009; Foster et al., 2008). Similar results have been found with children and young people experiencing physical health problems (Edgar, 2003; Neuhauser, Amsterdam, Hines & Steward, 1978). The relationships between primary and secondary appraisals, however, have not been well researched.

In adult mental health, secondary appraisals of illness also influence outcomes. Perceiving difficulties as long-lasting, uncontrollable and having significant consequences has been associated with greater affective disturbance and poorer adjustment, even in early psychosis groups (Lobban, Barrowclough & Jones, 2005; Stainsby, Sapochnik, Bledin & Mason, 2010; Watson et al., 2006). A recent general population study suggests that an internal locus of control is associated with reduced later impact of unusual experiences in children (Thompson et al., 2011). However, these kinds of appraisals and their impact have otherwise not been measured in children.

There are a number of routes by which illness perceptions and mental health stigma may interact. It is suggested that some negative illness perceptions relating to mental health (e.g. course, consequences or treatment control) may reflect elements of self-stigma in people with schizophrenia spectrum disorders and that this may mediate the effect of insight on depression (Cavelti, Beck, Kvrgic, Kossowsky & Vauth, 2012). It may be that stigmatising beliefs about mental health problems (for example that they are intractable, permanent problems which are inherently disabling) become internalised through the process described by Corrigan and colleagues (2002) and form part of the appraisal of one's own mental health 'threat'. Thus more stigmatising beliefs about others (SO) would be associated with more negative appraisals of one's own mental health problem, most likely through self-stigma (SS). However the association between stigma (both SS and SO) and illness perceptions has not otherwise been studied. Similarly, while there is a wealth of research on societal and self-stigma in adults and a growing research base in children and young people, there is little research on how personal stigmatising beliefs about mental health problems might impact upon a person who has PLEs, and how these beliefs might influence their appraisals of their experiences.

1.3 Summary and the current study

Based on a review of the current literature presented above, a substantial body attests to the importance of stigma in influencing adaptation to and recovery from mental health problems. The impact of stigma is especially pronounced for severe mental health problems, like psychosis, where societal understanding remains limited and misperceptions about the course and treatability of the disorder are prevalent, even amongst mental health staff.

Stigma has been demonstrated to exert its effects on mental health outcomes by multiple routes. At the societal level, stigma may lead to overt exclusion of individuals which reduces opportunities for engagement in recovery focused activities, or covert negative reactions, which may make such activities less enjoyable. Societal stigma may thereby increase social

isolation and drive avoidance and social withdrawal. These can be important factors in maintaining the mental health problem.

At the individual level, stigmatising attitudes towards others develop through the endorsement of societal stigmatising attitudes. Such attitudes influence appraisals of mental health problems, whether in others or in oneself. Negative appraisals of mental health problems in oneself, and of experiences associated with the mental health problem, can lead to self-stigmatisation and have been shown to lead to negative affective reactions (depression, anxiety, hopelessness) and to maladaptive behavioural responses (avoidance, withdrawal, non-engagement). Both the affective and behavioural reactions impede recovery and prevent adaptive coping, thereby maintaining the problem.

Cognitive models of psychosis emphasise the role of negative appraisals in the development and maintenance of psychosis. Pre-existing schematic beliefs and reasoning biases influence appraisals of experience, increasing the likelihood of external, personal and threatening primary appraisals of experiences, and more negative and hopeless secondary appraisals of the emerging 'problem'. Stigmatising beliefs about others can be considered to operate as a pre-existing belief, influencing appraisals of experiences and self-stigmatising beliefs are an example of negative secondary appraisals.

Cognitive therapy targets such appraisals in order to affect clinical improvement. Both the continuum models of psychosis underlying cognitive conceptualisations and the new NICE guidance for psychosis in people under 18 years old support the application of these ideas to distressing PLEs in young people. Although there is some debate over the meaning and status of PLEs in terms of future psychosis risk, developing interventions to reduce distress is less controversial. At most, intervention may reduce the future likelihood of developing psychosis; at least, it improves current wellbeing and functioning. The development of psychological therapies for young people with PLEs is therefore an important area for research.

Cognitive therapies specifically focussed on PLEs in young people are being developed and evaluated. Early evidence indicates that there are similarities between the emotional, social and cognitive processes demonstrated to contribute to the onset and maintenance of psychosis, and those influencing PLE severity. However the role of appraisal processes, and particularly the role of secondary appraisals, has not yet been considered in this area of research.

That such appraisals are likely to be very relevant to interventions with this group is evidenced by the research to date, demonstrating that in adolescence, when self-concept is developing and group membership is of paramount importance, stigma has been shown to be a particularly powerful influence on adaptation to mental health problems.

It is important to highlight that considering the impact of mental health stigma on PLEs is not to imply that PLEs are synonymous with mental health problems. PLEs, as discussed above, are common experiences in children and adolescents. Those who experience PLEs may go on to develop mental health problems but most will not. PLEs may, however, be viewed as sharing a phenotypic continuum with psychotic disorders and, as such, share some of the same characteristics. These characteristics may form some of the 'markers' described by Sartorius and Schulze (2005) by which young people identify mental health problems generally. Should the young person identify the PLE as possibly associated with a mental health problem, and have negative attitudes towards mental health problems, this may influence their appraisal and thus impact upon distress and coping.

1.3.1 *Aims of the present study*

The current study will examine personal beliefs about mental health problems, illness perceptions, and appraisals of experiences in a group of children recruited from community Child and Adolescent Mental Health Services (CAMHS). To the author's knowledge, this will be the first time that these factors have been examined together in a group of children in contact with mental health services. The first aim, therefore, will be to describe the characteristics of these children in relation to stigma, illness perceptions, appraisals of experiences and distress.

The second aim will be to investigate the relationships between stigmatising beliefs, primary and secondary appraisals and PLE severity and distress. This will be the first time this area has been investigated and, as outlined above, should be important in informing the further development of treatment approaches for these young people.

The final aim will be to investigate the associations between stigmatising beliefs about mental health problems held by the young person and their appraisals of their own experiences. This will help to understand how stigmatising beliefs form and how we may act to change them. In particular, contact with people with mental health problems has shown mixed effects on stigma in young people, so this study will include contact in order to add to this body of research.

In adults, perceived stigma, illness perceptions, and appraisals of unusual experiences have all been found to influence distress (Brett et al., 2007; Link & Phelan, 2001). This study will be the first to examine the relationship between these factors in a group of young people with unusual experiences.

It is noteworthy that, despite their hypothesised prognostic significance, PLEs are not usually routinely assessed in child and adolescent mental health services. The latest NICE guidance for psychosis for people under 18 years old suggests that psychological treatment should be offered to young people experiencing PLEs with distress and/or impairment (NICE,2013) and preliminary research suggests that treatment programmes can be implemented to treat the broad range of problems with which a young person with distressing PLEs might present (Maddox et al., in press). This study would therefore hope to inform such treatment programmes by elaborating on the relationship between distressing PLEs, appraisals and stigma.

1.3.2 *Hypothesised model*

Based on the existing literature, a theoretical model of associations between primary and secondary appraisals and PLE severity and distress and between SO and primary and secondary appraisals is presented in Figure 1.. It is hypothesised that the endorsement of societal stigmatising attitudes (SO) towards mental health problems in others influences the subsequent appraisal of one's own mental experience and increases the likelihood of self-stigmatising (SS) and negative appraisals. Such appraisals impact on symptom severity and distress. Symptom severity and distress will, in turn, act to further increase the likelihood of negative appraisals in what forms a vicious cycle.

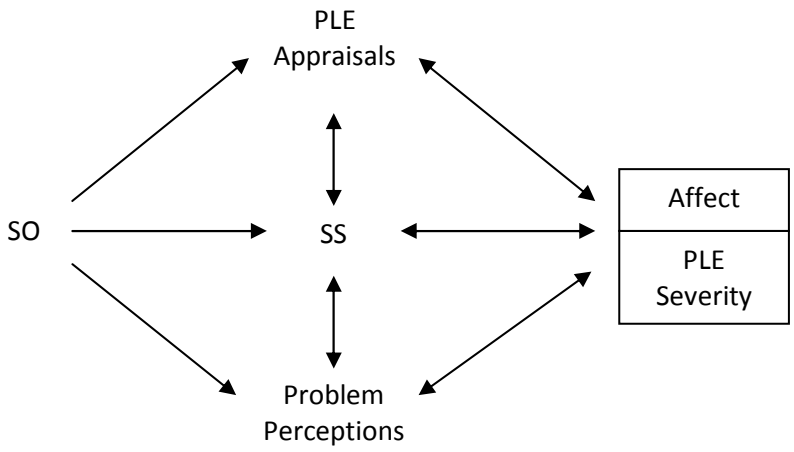

Figure 1.2: Hypothesised model of relationships between primary and secondary appraisals and PLE severity and distress
(SO= stigmatisation of others; SS= self-stigma; PLE= psychotic like experiences)

1.3.3 *Hypotheses*

This thesis is a test of the associations hypothesised in the model above and presented in Figure 1..

Firstly, it is hypothesised that self-stigma and appraisals will be associated with PLE severity and distress. In particular, it is predicted that more self-stigmatising beliefs (greater SS) will be associated with greater PLE severity and distress. It is also hypothesised that more external, personal and threatening appraisals of PLEs will be associated with greater PLE severity and distress and that more pessimistic problem perceptions will be associated with greater PLE severity and distress. The association between PLE appraisals and PLE severity and distress would constitute a replication of adult findings in young people with PLEs.

The second set of hypotheses concern the relationship between SO and appraisals. It is hypothesised that more stigmatising attitudes towards others (greater SO) will be associated with increased self-stigmatisation (SS). It is further hypothesised that greater SO will be associated with more external, personal and threatening appraisals of PLEs and with more pessimistic perceptions of problems.

Hypothesis 1

Self-stigma (SS) and appraisals will be associated with PLE severity and distress.

1a. Increased SS will be associated with greater PLE severity and distress.

1b. More external, personal and threatening appraisals of PLEs and more pessimistic problem perceptions will be associated with greater PLE severity and distress.

Hypothesis 2

Stigmatising attitudes towards others (SO) will be associated with self-stigma (SS) and appraisals.

2a. Greater SO will be associated with greater SS.

2b. Greater SO will be associated with more external, personal and threatening appraisals of PLEs and more pessimistic problem perceptions.

Hypothesis 3

Familiarity will be associated with SO.

Figure 1.3: Hypotheses to be tested

Finally it is hypothesised that familiarity with mental health problems will be associated with stigmatising attitudes towards others, though the relationship of this effect is uncertain given mixed findings from previous research.

2. METHOD

2.1 Statement of Contribution

The author (JB) developed the research question and selected and modified the appraisal questionnaires used for the present study with consultation from supervisors (SJ and SB). The author co-facilitated the service-user focus group (see Section 2.4) with a member of staff from the service and amended the measures in accordance with the feedback. Research workers were also trained and supervised in the use of the new questionnaires by the author until they had become proficient in their use. In addition, the author also directly recruited and assessed a number of the young people and families recruited to the study. Assessment of all participants included the full battery for CUES. All data collected was entered into an online database by the author or research workers (see Section 2.4.2) and was collated into SPSS and analysed by the author.

2.2 Participants

Participants in the present study were recruited as part of a larger study: the Coping with Unusual Experiences in Children Study (CUES). CUES was a randomised controlled trial of cognitive therapy for young people with unusual experiences and distress, with a baseline screening and assessment procedure designed to improve understanding of the psychological processes (cognitive, affective, social and behavioural) mediating the negative impact of PLEs in young people. Measures for the current study were administered as part of this larger battery for CUES assessing PLEs, affect, thinking style, life events, and coping behaviours.

The present study, as part of CUES, recruited children and young people aged 8-14 years from community child and adolescent mental health services (CAMHS) in the boroughs of Southwark, Lewisham and Croydon within the South London and Maudsley (SLaM) NHS Foundation Trust. These services provide outpatient assessment and treatment for people under the age of 18 years with emotional or behavioural problems. The services from which participants were recruited operate within a tier structure. Tier 1 refers to primary care (i.e. GP surgeries); Tier 2 operates as an assessment service. They do not usually work with young people with clearly diagnosable mental health problems, who are referred to a specialist team, and they typically receive referrals from GPs or schools. Tier 3 refers to the specialist teams and operates as the CMHT service for children and young people with mental health problems and Tier 4 is inpatient services. Participants for CUES were recruited from the waiting list of Tier 2 services. Ethical approval for CUES was granted by the London-Hampstead National Research Ethics Service (NRES) Committee (REC Ref 11/LO/0023) and Research and

Development approval was granted by the SLaM R&D committee (ref R&D2011/028) and the CAMHS Clinical Academic Group (CAG) (see Appendix 1). Recruitment was primarily from the services' waiting lists, although direct referrals from clinicians in the service were also accepted. Study protocols, Information Sheets and Consent forms for CUES are included in Appendices 2-7.

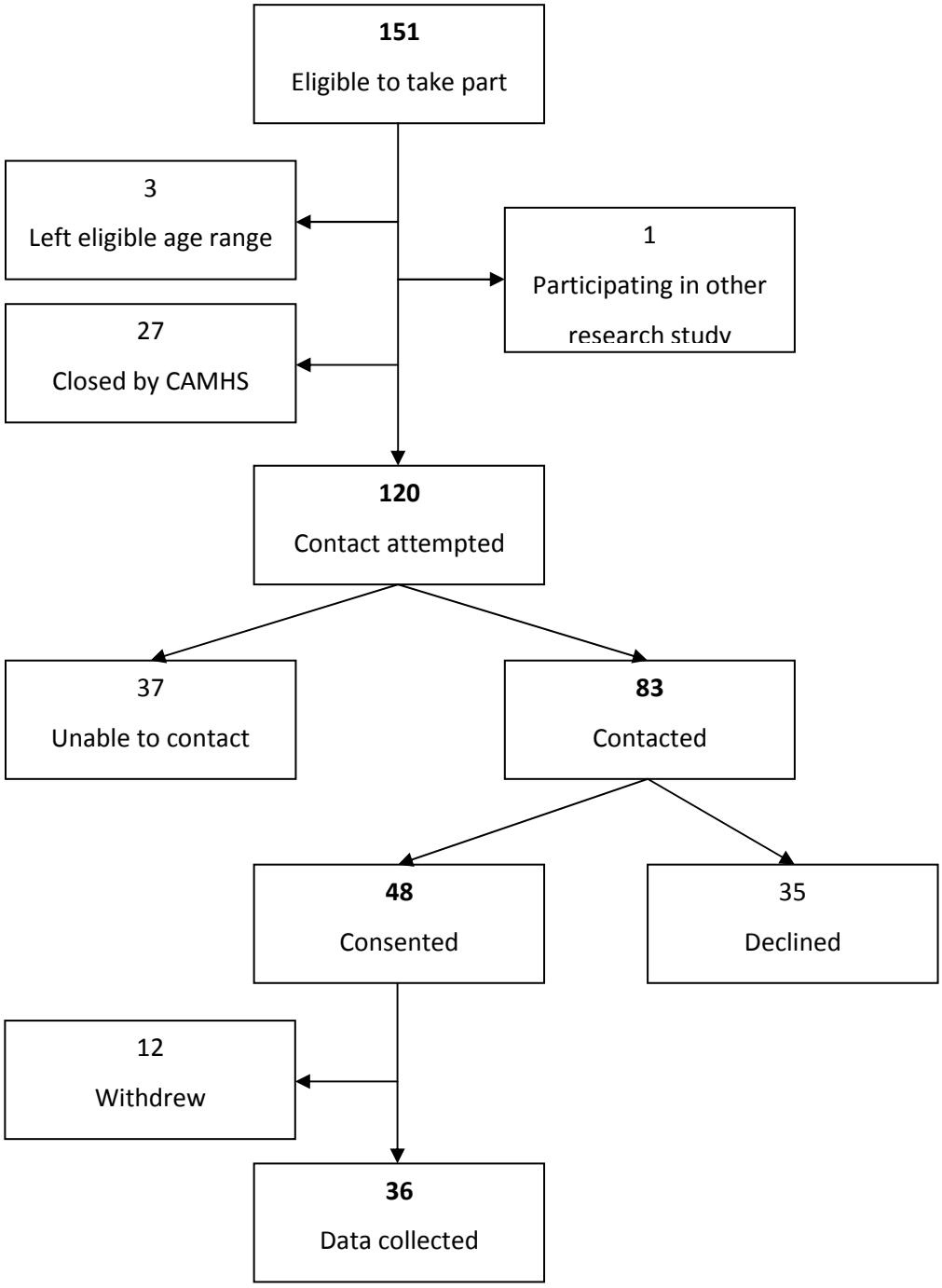

Figure 2.1: Recruitment flowchart

151 young people were identified as eligible to take part in the present study during the recruitment period for this study (see Figure 2.1). The families (or parental responsibility holders) of these young people were sent an information pack as described above and

telephone contact was attempted. Of those sent a pack, three left the eligible age range (i.e. turned 15 years old) before they could be recruited, one was recruited to another study and a further 27 cases were closed by CAMHS, making them ineligible for the current study; therefore attempts at contacting these young people were stopped. Of the remaining young people who were approached, 37 were not contactable by telephone and did not respond to letter contact; eighty-three were successfully contacted. Of these, 35 declined involvement, either on the telephone or after a face to face meeting to discuss the study. 48 young people were consented into the study. Of these, 10 later withdrew for practical reasons prior to the data collection commencing and two were withdrawn because of changes in their care arrangements with services. Thirty-six young people therefore provided data for analysis.

2.3 Measures

Demographic information was collected from parents or carers, from the clinical record (with consent) and from the young person directly. Remaining measures were completed by the young person with assistance from a trained researcher.

2.3.1 *Psychotic-like experiences (PLEs)*

PLE severity was assessed using a questionnaire developed by Laurens and colleagues (2007). This questionnaire includes five items adapted from the Diagnostic Interview Schedule for Children (Costello, Edelbrock, Kalas, Kessler & Klaric, 1982) and four assessing a wider range of PLEs (e.g. “Have you ever felt that you were under the control of some special power?” or “Do you have any special powers that other people don't have?”; see Appendix 8). Each PLE is rated on a three point scale of conviction (0= not true, 1= somewhat true, 2= certainly true). The measure has good internal consistency ($\alpha = 0.82$) and satisfactory agreement with clinical interview (Laurens, Hodgins, Maughan et al., 2007). Research has also demonstrated satisfactory construct validity based on item response theory (Laurens et al., 2012). For each PLE which the young person endorsed as somewhat or certainly true, follow-up questions were administered regarding the frequency, distress and functional impact of the PLEs based on previous work by Laurens and colleagues (2011). Responses for these were given on a four point scale (0-3, higher scores indicating greater frequency, distress or impact) and added to the conviction scores to give a measure of overall PLE severity, ranging from 0-99, with higher scores indicating greater severity.

2.3.2 *PLE appraisals*

Appraisals of the origin (internal versus external), causes (situational versus personal) and threat (benign versus dangerous) of PLEs were assessed for the most dominant PLE reported

by the participant (see Appendix 9). If more than one PLE was endorsed, the decision of which PLE was dominant was made by asking the participant which was the 'main' experience, or most upsetting. In other measures, such as the Appraisals of Anomalous Experiences Interview (Brett et al., 2007), externality, threat and agency are measured on a five-point scale based on a semi-structured interview. For this study, a similar five-point scale was used for ratings of externality (1= [cause is] completely because of something inside me, 5= completely because of something outside), agency (1= [cause is] completely other events, 5= completely what others are doing) and threat (1= [experience is] completely harmless, 5= definitely dangerous). Ratings were totalled to give an overall negative appraisal score ranging from 3-15, with higher scores indicating more external, personal and threatening appraisals.

2.3.3 *Negative affect*

Negative affect was assessed using two standardised measures of depression and anxiety. The Short Mood and Feelings Questionnaire (SMFQ; Angold et al., 1995) is a self-report questionnaire developed to screen for depression in young people aged 8-18 years. It consists of thirteen items in which the young person is asked to respond on a three point scale (0= not true, 1= sometimes, 2= true). The reliability and validity of the measure as a screen for depression has been well documented in British children (Kent, Vostanis & Feehan, 1997; Wood, Kroll, Moore & Harrington, 1995). The Spence Children's Anxiety Scale (SCAS; Spence, 1998) is a self-report questionnaire comprising 38 items measuring levels of obsessions or compulsions, social phobia, panic or agoraphobia, separation anxiety, physical injury fears and generalised anxiety, with 6 positive 'filler' items. Young people respond on a four-point scale (0= never, 1= sometimes, 2= often, 3= always). A total anxiety score ranging from 0-114 can be calculated; as the current study required an assessment of overall distress, the total score was used in preference to subscale scores. Non-clinical means range from 21 (older boys) to 34 (younger girls); clinically significant anxiety is indicated by scores 1 or more standard deviations above the mean. This questionnaire has been validated in children aged 8-12 years (Spence, 1997, 1998) and in UK children aged 12-17 years (Essau, Sasagawa, Anastassiou-Hadjicharalambous, Guzmán & Ollendick, 2011).

2.3.4 *Problem severity*

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) was used to assess the severity of emotional and behavioural problems in the sample. The SDQ is a screening questionnaire which can be administered to parents, teachers or young people to assess for emotional and behavioural problems. The questionnaire consists of twenty-five items divided equally between five subscales: emotional symptoms, conduct problems,

inattention/hyperactivity, peer relationship problems and prosocial behaviours. Each item requires the person to respond on a three-point Likert scale (0= not true, 1= somewhat true, 2= certainly true). Scores can be calculated for each subscale or by adding scores for the first four subscales to give an overall problem score. Scores of 20 and above are considered to represent clinically significant difficulties; scores of 16-19 are 'borderline'. The psychometric properties of the SDQ have been tested in large samples of 11-15 year olds (Goodman, Ford, Simmons, Gatward & Meltzer, 2000; Goodman, 2001) and, with reduced reliability but otherwise satisfactory psychometric properties, in children as young as 7 years (Mellor, 2004; Muris, Meesters, Eijkelenboom & Vincken, 2004; Van Roy, Veenstra & Clench-Aas, 2008).

2.3.5 *Illness/problem perceptions*

The Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main & Weinman, 2006) was used to measure secondary appraisals based on the self-regulation model proposed by Leventhal and colleagues (1997). Single items tap seven dimensions of appraisals (consequences, timeline, personal control, treatment control, illness comprehensibility, concern and emotions), rated from 0-10, which can be totalled to provide a measure of overall threat appraisal with higher scores representing more negative illness perceptions. One item relating to symptoms was removed as such an item was not relevant to an undiagnosed group. The language of the questionnaire was also modified to avoid the medicalised term "illness" by replacing this word with "problems". This is common practice when using the measure with a mental health group (Freeman et al., 2012; Watson et al., 2006). The Brief IPQ has been widely used in a range of health conditions, and the full IPQ is commonly used with children with physical health conditions. Research has demonstrated good test-retest reliability as well as good concurrent validity with longer versions and predictive validity in physical health problems (Broadbent et al., 2006). Research has also demonstrated that longer versions can be usefully adapted for mental health problems and such adaptations reliably measure adolescents' perceptions of their problems (Lobban et al., 2005; Witteman, Bolks & Hutschemaekers, 2011). Since a total score was being used, the internal consistency was checked and found to be satisfactory (α= 0.81).

2.3.6 *Stigma*

For the current study we wished to measure both stigmatising attitudes towards mental health problems and self or self-stigma. There is no widely accepted and validated measure of either of these constructs in young people. Measures were therefore developed based on existing measures which tap different constructs of stigma.

2.3.6.1 Stigma of others with mental health problems (SO)

A review of existing measures of SO, which tend to be vignette-based, highlighted difficulties with using either a set of behaviours (e.g. Jorm & Wright, 2008), which may not match the child's perception of the relevant label, or a label (e.g. Corrigan et al., 2005), which may prime stigmatising attitudes (Wahl, 2002). A combined measure was therefore developed for the present study based on existing materials.

A vignette-based questionnaire was chosen as the measurement method for SO. The behaviours chosen for the vignette were developed by agreement with clinical psychologists with experience of working with young people and checked against young people's perceptions through a focus group (see Section 2.3). Since the measure utilised methods including behaviours and labels, the questions which followed were therefore amalgamated from questionnaires using both methods. These included nine items from the revised Attribution Questionnaire (Corrigan, Lurie et al., 2005; Watson et al., 2004) with wording slightly amended to be accessible to a younger age group. One item relating to attitudes towards seeking treatment was removed to avoid this being interpreted as a suggestion that the young person had a mental health problem. One item was also changed to refer to segregation by a person with a mental health problem being in a "special school for people with mental health problems" rather than a "mental hospital". Since items on this measure were mostly negatively worded, four items were added relating to inclusion and acceptance of people with mental health problems. The items from the revised Attribution Questionnaire overlap with items from specific research on mental health stigma in children (Jorm & Wright, 2008), though the latter included a specific item on unpredictability. Since research on stigma in young people has often combined dangerousness and unpredictability and found unpredictability stereotypes to be more commonly endorsed for people with psychosis (Jorm & Wright, 2008; Link, Yang, Phelan & Collins, 2004; Watson et al., 2004; Wright, Jorm & Mackinnon, 2011) it was decided to add this item to the questionnaire. This ensured the final questionnaire measured the same constructs as existing questionnaires.

In order to avoid the acknowledged problem of social desirability (the tendency for children to answer self-report questionnaires based on what they believe they should say in order to present a certain image of themselves (Tourangeau & Yan, 2007)), it was emphasised that there were no "right answers" and that all responses were anonymous. While more recent measures have been developed in an attempt to specifically address social desirability in mental health stigma research (Michaels & Corrigan, 2013), such scales were not available at the time of selection of the measures used in the present study and, in any case, tend to focus

on knowledge of, rather than attitudinal and behavioural responses to, mental health problems.

In the finalised measure, participants were first presented with a vignette asking them to imagine a young person – "Alex" – joining their class who has a label of a mental health problem and describing behaviours they might display (see Appendix 10). Participants were then presented with 14 statements relating to their attitudinal and behavioural responses to Alex. Responses were given on a five-point Likert scale (1= strongly disagree, 5= strongly agree) with the scoring reversed for positively worded items. Scores on each item were totalled to give an overall score (minimum= 14, maximum= 70), with higher scores indicating greater stigmatising of mental health problems by the participant. While validation of the revised Attribution Questionnaire is still in its infancy, there is some emerging evidence supporting the validity of its factor structure (Pinto, Hickman, Logsdon & Burant, 2012). In light of the amendments made for the current measure, the internal consistency was checked for the current sample and was found to be satisfactory (α= 0.79).

2.3.6.2 Self-stigma (SS)

The paucity of research on this phenomenon in young people means that no single measure has solid empirical support (Mukolo et al., 2010). So far research has utilised either interview methods (e.g. Green et al., 2003) or adapted child stigma measures from other disorders (e.g. Moses, 2009, 2010). Popular and well validated mental health stigma measures used in adult studies (e.g. Boyd Ritsher, Otilingam & Grajales, 2003; Corrigan, Watson & Barr, 2006) are lengthy, use adult language, and have yet to be properly validated in children and young people.

For the present study, the Self-stigma of Mental Illness scale (ISMI; Boyd Ritsher et al., 2003) was piloted on a group of young people (see Section 2.3). This twenty-nine item questionnaire was originally developed in collaboration with people with mental health problems to measure subjective experience of stigma by eliciting responses to statements about such experiences on a Likert scale. The responses given can be totalled and averaged to give an overall score or split into five subscales of alienation, stereotype endorsement, discrimination experience, social withdrawal and stigma resistance. The measure has demonstrated excellent test-retest reliability (r= 0.92), internal consistency (α= 0.90) and construct validity in adults (Boyd Ritsher et al., 2003) but was considered too long by both CAMHS clinicians and service user advisors. A shorter version was therefore developed by selecting the two highest loading items for each subscale (see Appendices 11-12).

The finalised self-stigma measure consisted of ten items in which the participant responded to various statements about their experiences of problems which had led them to come into contact with services (mental health or ill-health was not referred to in this questionnaire). Participants responded on a five point Likert scale of agreement (1= strongly disagree; 5= strongly agree), with scoring reversed on the positively worded stigma resistance item. Scores were then totalled and averaged to give a mean score (minimum= 1, maximum= 5), with higher scores indicating greater SS. The amended scale showed satisfactory internal consistency in the present sample (α= 0.81).

2.3.7 *Familiarity with Mental Health Problems*

This was measured using the level of contact report (Holmes, Corrigan, Williams, Canar, & Kubiak, 1999). Participants check all the statements about contact with people with mental health problems which are true for them, ranging from low contact (e.g. "I have watched a movie or television show in which a character depicted a person with a mental illness") to high contact (e.g. "I have a relative who has a severe mental illness"). Statements are scored sequentially in order of increasing levels of contact based on agreement between three experts in mental health in the original study (Holmes et al., 1999). The participant scores according to the highest level of contact, regardless of the frequency or nature of the experience. Language was adapted slightly to be more accessible to younger people (e.g. replacing "observed" with "seen") and the term "mental illness" was changed to "mental health problem". Originally consisting of twelve statements, two items were removed as they refer to working in paid employment with people with mental health problems, which is not relevant to this sample. A third statement ("I worked with a person who had a severe mental illness at my place of employment") was changed to "I go to school with someone with a mental health problem" to make it more relevant to young people.

2.4 Service User Involvement

Since the stigma measures were either adapted or not well validated in young people, they were evaluated in a focus group to maximise their accessibility, acceptability and validity for young people. The focus group was run with service users to discuss their views of the questionnaires and how they might be amended for other young people. The young people involved in the focus group were invited from a CAMHS inpatient ward in the SLaM NHS Foundation Trust, working with young people aged 12-18. Nursing staff invited all young people on the ward to take part, describing the activity as 'a focus group to involve service users in the development of questionnaires'. Service users were informed of the study aims

and those who attended the group were asked to sign local standard assent forms indicating that they were volunteering for the group (see Appendix 13). Where possible, verbal consent was also obtained from parents but young people were not excluded from the group if they wished to participate and their parents could not be reached before the focus group, providing the clinical team considered this to be appropriate.

The focus group took place on the ward. Six young people attended the group (2 male, 4 female). The ages of the young people in the focus group was older than the intended participant group for the study (mean= 16.17 years, range= 14-17 years) but they were asked to consider the suitability of the measures for children younger than themselves. Participants were invited to complete all questionnaires first, with the specific assurance that their responses would not be used in the study and that they could keep their questionnaire if they preferred. Participants were then asked to make any corrections or notes directly onto the questionnaires if they wished and then to complete a short questionnaire on their thoughts about them (e.g. “did the questions make sense?”, “were there any questions you thought shouldn’t be there?” See Appendix 14). Finally, the group finished with an open discussion about the questionnaires. Special attention was given to any suggestions from younger group members about improving the accessibility of the wording. From the focus group, the following amendments were made to the wording and structure of the stigma vignette questionnaire:

- The young person’s name in the vignette was chosen as “Alex” so it is gender neutral. All third person possessive pronouns were consequently changed to “their” rather than “his” or “her” to maintain neutrality.

- “Alex would annoy me” was changed to “Alex’s problems would annoy me”. The group members reported that they could not answer the former statement since they did not know Alex; therefore the statement should be linked more explicitly to Alex’s mental health problem.

- “Alex is no different to any other person in my class” was changed to “Alex is just like any other person in my class”. Group members reported the wording of the latter statement was more accessible.

The following amendments were made to the modified ISMI:

- The measure was reduced to ten items as twenty-nine was agreed to be too long by the group members.

- The response scale wording was changed from “disagree” and “agree” to “disagree a bit” and “agree a bit” as the group agreed this gave a more even distribution for strength of agreement with each item.

- The response scale was also increased from four-point to five-point. “Don’t know” was added as the middle point as the group agreed this option was needed and was present in the stigma vignette.

2.5 Procedure

2.5.1 *Recruitment*

Children and young people aged 8-14 years were recruited from the waiting list of the CAMHS teams. The CUES protocol was to approach all families on the waiting list within the age range for screening for the trial, although some were discharged from CAMHS before they could be approached (see Figure 2.1). Parental responsibility holders were sent information sheets for both themselves and the young person, together with the consent and assent forms. They were then contacted by telephone a week later to answer any questions they might have and invite them to take part in the study.

If the carer and young person wished to take part in the study, they met with a member of the research team to go through the information sheets and answer any further questions. These meetings were carried out at either the local CAMHS team or at home, whichever was preferred by the carer. It was made clear during this meeting that CAMHS involvement would not be affected by participation or non-participation in the study and that they could withdraw at any time from the study without this disadvantaging their receipt of other services in any way, and without giving a reason. They were also informed that their assessment or treatment by CAMHS would not be delayed by participation. Confidentiality was discussed and it was made particularly clear that risk information would need to be communicated to the CAMHS team as they would be care-coordinators for the young person. Following the above discussion, if the carer and young person were in agreement, informed consent and assent were obtained from the carer and young person.

2.5.2 *Protocol*

The above measures formed part of a wider battery for the screening assessment of participants in CUES. The CUES protocol was to re-administer the battery at three-month follow-up and one-month post-intervention but data for the present study were collected only at baseline. The CUES battery included neuropsychological, social, emotional and cognitive measures to gain a detailed understanding of any differences between young people with and without distressing PLEs. A complete list of CUES measures is given in Appendix 15. Data for the measures used in this study were collected using an online survey (SelectSurvey.Net 2.8.5) administered via an iPad2 (© Apple Inc.) with paper copies available in the event of technical failure. Measures were designed to be visually engaging for participants by using varied fonts and colours and punctuating the survey with pictures relaying positive feedback for completing questionnaires. The battery was typically administered over three sessions of around an hour each. Sessions were punctuated with breaks at intervals based on the participant's engagement and fatigue. After the first session, for which a carer's presence was required, school visits were offered if this was more convenient for the carer and young person. A strict administration order was not adhered to for the battery to give researchers maximum flexibility in tailoring the length and content of sessions to the young person's engagement pattern. However the SDQ was usually administered in the first session, and the PLE questionnaire in the second session, once the participant had been sufficiently engaged. The stigma questionnaires were most commonly administered later in the battery. Before administering the stigma questionnaires, it was explained to the young person that they would be asked what they thought about the difficulties that had brought them into contact with the CAMHS team and their perceptions of mental health problems. It was made clear that the researcher did not mean to imply that the young person had a mental health problem themselves. On completion of the battery all participants were given their choice of a £5.00 voucher for the cinema or for a stationery shop.

2.6 Statistical analyses

All statistical analyses were carried out using SPSS version 20 (IBM, 2011). For each hypothesis, both the primary and secondary analyses were correlations.

Since much of the data in the present sample was not normally distributed (see section 2.5.3), many of the relationships could not be tested using parametric analyses. Spearman's rank correlations were therefore employed. The boundary for significance was held at p= 0.05 for the primary hypothesis, however the running of multiple tests increases the risk of a Type I error (Field, 2005, p. 310), therefore a stricter value of p= 0.01 was applied for statistical

significance in secondary analyses. While values below p= 0.05 would still be of interest, they must be interpreted with caution in light of multiple testing.

Post hoc analyses were carried out to assess the independence and predictive value of SS on PLE severity. A regression analysis could not be conducted for the primary hypothesis as there was heteroscedasticity in the data, which violates the assumptions of a regression analysis. In order to assess whether the relationship between self-stigma and PLE severity still held when controlling for SO, a Spearman's rank partial correlation was conducted. A regression analysis was used where appropriate to test the independence of SS in predicting PLE severity and to check that the association was not an artefact of a common association with affective disturbance. While PLE severity was not normally distributed, the distribution of errors within the model was satisfactory with no significant outliers (see Appendix 16.8). The regression was conducted using the forced entry method to include all variables. For such analysis, 10 participants would be required per predictor variable.

The effects of demographic variables on SO, self-stigma and PLE severity were investigated to assess whether these would need to be controlled for in the analyses (see Appendices 16.1-16.3). A Spearman's correlation revealed no significant effect of age on self-stigma, SO or PLE severity. An independent samples t-test was carried out to test for any gender differences on the same measures. No significant gender differences were found on any of the measures used for the primary hypothesis. Finally, the same measures were assessed for ethnicity differences. Since the numbers within each ethnicity group were insufficient for comparison using an ANOVA, data was recoded to investigate whether scores on the primary measures were significantly different for white British or Irish participants to participants from any other ethnicity using an independent samples t-test. No significant effect was found for ethnicity on any of the primary measures. Demographic variables were not therefore controlled for in any of the reported analyses.

2.6.1 *Power calculations*

Power calculations were computed using G*Power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009). Since associations between stigma and PLE severity have not previously been tested in research, the strength of association could not be predicted from the literature. However, appraisals of anomalous experiences have been demonstrated to discriminate between levels of severity of anomalous experiences with an effect size of 1.0, indicating that it is plausible to hypothesise that effect sizes will be moderate to large. For primary and secondary analyses, a bivariate correlation demonstrating a moderate to large correlation (as defined by Cohen,

1992) of 0.45 between stigma and PLE severity, with 80% power at a significance level of α= 0.05 requires a sample size of 29 (lower critical r= -0.37; upper critical r= 0.37).

2.6.2 *Missing data*

There were instances where certain measures were not administered, either due to technical error in the online survey (seven cases) or because the participant declined to complete further questionnaires and this was permitted in order to maintain engagement in the larger study (eight cases). Appraisal data were missing for a further five participants. The only measure in which individual items were missing was the BIPQ. It was noted in administration that participants could find answering some of these questions difficult if they did not think of themselves as having any problems. In these cases, if only one item was missing (one case) it was replaced with the mean; otherwise the data was classed as missing (one case). Missing data is presented by measure in Table 2.1.

Table 2.1: Missing data by measure

Measure	Number providing data	Number missing
SDQ	35	1
PLE Severity	35	1
PLE Appraisals	19	7
SMFQ	36	0
SCAS	35	1
Stigma measure	32	4
Self-stigma measure	29	7
Familiarity	32	4
BIPQ	31	5

SDQ= Strengths and difficulties questionnaire; PLE= psychotic-like experience; SMFQ= moods and feelings questionnaire; SCAS= Spence children's anxiety scale; BIPQ= Brief illness perception questionnaire

2.6.3 *Distribution of data*

Skewness and kurtosis statistics for each variable are shown in Appendix 16.4, as are Kolmorgorov-Smirnov and Shapiro-Wilk tests of significance. The measures in which data did not deviate from a normal distribution were age, SO, anxiety, SDQ hyperactivity, SDQ peer problems and overall SDQ score. PLE conviction, upset and impact were all noted to be significantly positively skewed, as was data on the MFQ. Outliers were searched for by standardising data to z scores and inspecting these for any values greater than 3.29 (Field,

2005, p. 76) but none were found. In light of the distribution of data violating the assumptions of parametric tests (i.e. that data is normally distributed), all correlations were carried out using a Spearman's correlation.

3. RESULTS

3.1 Characterising the sample

3.1.1 *Clinical and Demographic Characteristics*

A total of 36 participants (25 male, 11 female) were recruited from community CAMHS. Descriptive statistics for age and SDQ scores are shown in Table 3.1. The male to female ratio of the sample was 2.27:1. The most common ethnicity was white British or Irish (n= 17) followed closely by black or black British of Caribbean or African origin (n= 14). The remaining reported ethnicities were Asian or Asian British of Indian, Pakistani or Bangladeshi origin (n= 1) and mixed white and either Caribbean, African or Asian (n= 1). Ethnicity was not recorded for three participants. Half of participants scored at or above the borderline range for self-reported emotional problems and/or overall problems on the SDQ. A quarter of participants scored in the clinical range for emotional, conduct and/or overall problems.

Table 3.1: Demographics and clinical characteristics of the sample

	Mean (SD)	Median	Mean (SD) from community sample[2]
Age	11 years, 4 months (2.00)	11 years, 5 months	
SDQ Subscales			
Emotional Problems	4.91 (2.55)	6.00	2.6 (2.1)
Conduct Problems	3.09 (2.13)	3.00	2.2 (1.6)
Hyperactivity	4.60 (2.60)	5.00	3.7 (2.3)
Peer Problems	3.09 (1.76)	3.00	2.0 (1.7)
Prosocial Behaviours	7.40 (2.32)	8.00	7.4 (1.7)
Total SDQ[3]	15.69 (6.22)	16.00	10.4 (5.4)

SDQ= Strengths and Difficulties Questionnaire

[2] (Muris et al., 2004). Figures reported to one decimal place.
[3] SDQ scores calculated with one fewer participants (n=35) than age (n=36).

3.1.2 *Psychotic-like experiences (PLE) severity and distress*

Descriptive statistics for subscales of the PLE measure and affective disturbance on the SMFQ and SCAS are shown in Table 3.2.

Of the present sample, 78% reported experiencing at least one PLE and 68% reported two or more. PLEs were experienced in the last fortnight by 68% of participants. Of the participants who had experienced PLEs, 41% reported "quite a lot" or "a great deal" of upset and 34% reported "quite a lot" or "a great deal" of impact on their home or school life.

The most frequently endorsed PLE was 'being able to read others thoughts' (n= 18) followed by 'having thoughts read by others' and 'seeing something or someone others did not' (both n= 15). The remaining PLEs, in descending order of frequency were 'hearing voices that others cannot hear' and 'being followed or spied upon' (both n= 14), 'having special powers' (n= 13), 'being under the control of some special power' and 'feeling as though their body had changed in a way they did not understand' (both n= 10). 'Being sent special messages through the television' was the least frequently reported PLE (n= 9).

Table 3.2: Descriptive statistics for PLEs and affective disturbance

	N	Mean	Standard Deviation	Range (min-max)	Possible Range (min to max)
PLEs	35				
Conviction		4.54	4.19	0-14	0-18
Frequency		4.69	4.68	0-14	0-27
Upset		2.66	3.46	0-11	0-27
Impact		2.54	3.35	0-11	0-27
Total Severity		14.43	14.71	0-44	0-99
SMFQ	36	6.78	6.01		
SCAS	35	32.91	17.12		

PLE= psychotic-like experience; SMFQ= short moods and feelings questionnaire; SCAS= Spence children's anxiety scale

On the SMFQ, the mean score of the sample fell just below the clinical cut-off score of eight suggested by Angold and colleagues (1995). Descriptive statistics for individual subscales of the SCAS are shown in Appendix 16.5. The sample here is not directly comparable to previous

community studies of anxiety using the SCAS, but the mean total score for participants aged 8-12 years (mean= 33.60; s.d.= 17.12) was comparable to a clinical sample and higher than non-clinical controls from an Australian study (Spence, 1998). However, a large scale community study found significantly higher mean total scores for UK children than those from other European countries (Essau et al., 2011), which may explain this difference. In fact, the mean total score for those aged 12 years and above in the present sample (mean= 33.71; s.d.= 18.67) was comparable to the community sample of children (aged 12-17 years) in the UK (Essau et al., 2011).

3.1.3 *Appraisals - stigma*

Descriptive statistics for stigma measures are shown in Table 3..

Table 3.3: Descriptive statistics for stigma measures

	N	Possible Range	Range	Mean	Standard Deviation
SO	32	14-70	16-53	30.38	8.96
SS	29	1-5	1.1-4.2	2.53	0.90
Familiarity	32	1-10	1-10	5.75	2.90

SO= stigmatisation of others; SS= self-stigma

3.1.3.1 Stigmatisation of others (SO)

Item-level descriptive statistics are displayed in Appendix 16.6. All participants reported some stigmatisation of others. The most frequently endorsed stigma item was on the theme of segregation ("Alex belongs in a special school for people with mental health problems"; n= 14) followed closely by unpredictability (n= 13). The highest average level of agreement was with unpredictability.

3.1.3.2 Familiarity with mental health problems

Only five participants reported having no contact at all with people with mental health problems. Three participants identified themselves as having mental health problems. The most commonly reported form of contact was seeing someone they thought had a mental health problem (n= 18). The next two most common forms of contact were seeing a television programme about mental health (n= 15) or a character on a programme who had a mental health problem (n= 12). These were all classed in the lower half of the spectrum of contact with people with mental health problems.

3.1.3.3 Self-stigma

Item-level descriptive statistics are displayed in Appendix 16.7. The most frequently endorsed items were 'being unable to live a good, happy life' (n= 13) and 'being annoyed at myself for having problems' (n= 12). The mean average score fell between a neutral response and mild disagreement with self-stigma statements.

3.1.4 *Appraisals – problem perceptions*

The domain in which participants reported greatest concern relating to their problems was within treatment control and emotional consequences. Descriptive statistics for individual subscales are shown in Table 3..

Table 3.4: Descriptive statistics for domains of the Brief IPQ

Brief Illness Perceptions Questionnaire (BIPQ) Subscale	Mean	Standard Deviation
Consequences	4.64	2.78
Timeline	4.79	3.27
Personal Control[a]	4.73	3.16
Treatment Control[a]	3.44	2.93
Concern	4.61	3.59
Comprehension[a]	4.45	3.77
Emotions	6.03	3.31
Total BIPQ Score	33.26	14.82

[a] Items are positively worded and reversed scored in the present study. Higher scores in each item therefore indicate greater pessimism or concern within the domain.

3.1.5 *Appraisals – Psychotic-like experiences (PLEs)*

Participants' appraisals are summarised in Table 3.. The mean scores on each subscale tended towards neutral appraisals of PLEs (i.e. participants were unsure whether their experiences originated internally or externally, were caused by uncontrollable events or other people, or were benign or dangerous). However, scores were distributed across the range of the measure, with more than half of participants scoring above the midpoint (i.e. making predominantly negative appraisals) on one or more scales.

Table 3.5: Descriptive statistics for PLE appraisals

	N	Mean	Standard Deviation	% Making Negative Appraisal
Externality	19	3.11	1.45	37
Agency	19	3.05	1.35	37
Dangerousness	19	3.16	1.50	58
Total Appraisal Score	19	9.32	2.52	

3.2 Main hypotheses

3.2.1 *Hypothesis 1: Self-stigma (SS) and appraisals will be associated with PLE severity and distress.*

3.2.1.1 *Hypothesis 1a: More self-stigma (SS) will be associated with greater PLE severity and distress.*

The primary hypothesis was that self-stigma (stigmatisation of self, SS) would be associated with PLE severity. A significant relationship was found between SS and PLE severity (see Table 3.). There was a moderate to large correlation between SS and PLE severity such that greater SS was associated with greater PLE severity. It was also hypothesised that SS would be associated with affective disturbance. A significant and strong relationship was found between self-stigma and affective disturbance on the depression measure but not the anxiety measure (see Table 3.). Increased self-stigma was associated with higher depression scores.

Table 3.6: Spearman's correlations illustrating the influence of self-stigma and appraisals upon PLE severity and affective disturbance

		PLE Severity	SMFQ	SCAS
SS	r_s	0.53	0.65	0.33
	p	0.003**	<0.001**	0.080
	n	29	29	29
PLE Severity	r_s		0.45	0.46
	p		0.006**	0.007**
	n		35	34

SS= self-stigma; PLE= psychotic-like experiences; MFQ= moods and feelings questionnaire; SCAS= Spence children's anxiety scale

** p< 0.01

3.2.1.2 *Hypothesis 1b: More negative appraisals of PLEs and more negative problem perceptions will be associated with greater PLE severity and distress.*

Secondary hypotheses concerned the replication of relationships previously demonstrated in adults between appraisals and symptom severity and distress. A significant and strong

relationship was found between PLE appraisals and anxiety on the SCAS but not depression. A correlation coefficient of a medium size was found between PLE appraisals and severity in the expected direction (with greater PLE appraisal being associated with greater overall external, personal and threatening appraisals), but this did not reach significance (see Table 3.). Numbers were reduced for this analysis as data could only be taken from participants who were experiencing PLEs.

A significant, moderate to strong relationship was found between problem perceptions on the BIPQ and anxiety, with a trend towards significance for the correlation between BIPQ and depression scores. More negative problem perceptions were associated with increases in both depression and anxiety scores. No significant relationship was found between problem perceptions and PLE severity.

Table 3.7: Spearman's correlations between PLE severity and appraisals

		PLE Severity	SMFQ	SCAS
PLE Appraisals	r_s	0.376	0.098	0.63
	p	0.112	0.690	0.006**
	n	19	19	18
BIPQ	r_s	0.10	0.41	0.46
	p	0.59	0.022*	0.009**
	n	30	31	31

PLE= psychotic-like experiences; SMFQ= short moods and feelings questionnaire; SCAS= Spence children's anxiety scale; BIPQ= brief illness perceptions questionnaire

* Trend towards significance (p< 0.05); ** p< 0.01

3.2.2 *Hypothesis 2: Stigmatising attitudes towards others (SO) will be associated with self-stigma (SS) and appraisals*

3.2.2.1 *Hypothesis 2a: More stigmatising attitudes towards others (SO) will be associated with more self-stigma (SS)*

A trend towards a significant relationship was found between SO and SS. There was a moderate to large correlation between SO and SS, such that increased SO was associated with increased SS. (see Table 3.8). However, this did not reach the stricter α level of 0.01.

Table 3.8: Spearman's correlations illustrating associations between stigma, and appraisals

		SS	BIPQ Total	PLE Appraisals
SO	r_s	0.45	0.13	0.19
	p	0.020*	0.51	0.50
	n	27	29	15

SO= stigmatisation of others; BIPQ= brief illness perceptions questionnaire; PLE= psychotic-like experiences

* Trend towards significance (p< 0.05)

3.2.2.2 *Hypothesis 2b: More stigmatising attitudes towards others (SO) will be associated with more external, personal and threatening appraisals of PLEs and more negative problem perceptions.*

No significant relationship was found between SO and either problem perceptions or PLE appraisals (see Table 3.8).

3.2.3 *Hypothesis 3: Familiarity with mental health problems will be associated with stigmatising attitudes towards others (SO).*

The final hypothesis was that familiarity would be associated with SO, though the direction of this relationship was uncertain based on the literature. Contrary to previous research, no significant relationship was found between familiarity with mental health problems and SO ($r_s[30]= –0.275$, p= 0.142).

3.3 Post hoc analyses

Since SO was associated with SS but, contrary to the hypothesised pathway, was not found to be associated with either problem perceptions or PLE appraisals, this raised a question as to whether SS might be associated with the other appraisals. If not, it would suggest that the influence of societal stigma is solely upon self-stigmatising attitudes, which then influence other appraisals. A Spearman's correlation was therefore carried out to test the relationship between these variables (see Table 3.). A trend towards a significant relationship was found between SS and problem perceptions, with more negative problem perceptions being associated with increased SS. However, no significant relationship was found between SS and PLE appraisals.

Table 3.9: Spearman's correlations between SS, PLE appraisals and problem perceptions

		BIPQ Total	PLE Appraisals[4]
SS	r_s	0.392	0.009
	p	0.043*	0.974
	n	26	16

SS= self-stigma; BIPQ= brief illness perceptions questionnaire; PLE= psychotic-like experiences* Trend towards significance (p< 0.05)

Further post hoc analyses were carried out to assess the independence and predictive value of SS on PLE severity. A Spearman's rank partial correlation revealed that the relationship between self-stigma and PLE severity still held when SO was controlled for (r(24)= 0.611, p= 0.001). SO was not independently related to PLE severity (r=0.18, p=0.32).

Since SS was found to be associated with both affective disturbance and PLE severity, and as affective disturbance is a known correlate of PLE severity, a regression analysis was conducted with PLE severity as the dependent variable and SS, depression and anxiety as the predictor variables. The association of SS with PLE severity remained consistent when the contribution of affective disturbance was controlled. The output of this regression can be seen in Table 3. (see Appendix 16.9 for the full regression summary).

Table 3.10: Regression coefficients for SS and affective disturbance as predictors of PLE severity

		B	SE B	β	t	p
Model 1	**SS**	7.51	3.31	0.46	2.27	0.03
	SMFQ	0.19	0.54	0.08	0.35	0.73
	SCAS	0.23	0.15	0.27	1.56	0.13

SS= self-stigma; SMFQ= short moods and feelings questionnaire; SCAS= Spence children's anxiety scale

The predictive model which included SS, depression and anxiety explained 46% of the variance in PLE severity (F[3]= 7.20, p= 0.001). The regression coefficients shown in Table 3. suggest that SS remained a significant contributor to the model when depression and anxiety are controlled for, while anxiety and depression did not. However this result should be interpreted with caution as the high correlation between SS and depression scores means that there may be multicollinearity which is biasing the model (Bowerman & O'Connell, 1990).

[4] PLE appraisals data were only taken from those participants reporting PLE's, therefore the numbers available for analysis are smaller than in other correlations.

4. DISCUSSION

4.1 Summary of study and results

This study examined the influence of stigmatising beliefs about others and the self, together with primary and secondary appraisals, on the severity of psychotic-like experiences (PLEs) and distress in young people attending community Child and Adolescent Mental Health Services (CAMHS). Specific predictions, derived from a hypothesised model of these associations, were tested. This is the first time these factors have been examined together in such a group. The overall goal was to inform the development of cognitive behavioural interventions for this group of young people.

The first aim was to describe the primary and secondary appraisals of presenting problems in a clinically-referred but otherwise non-clinical group of children and young people attending community CAMHS. It was hypothesised that appraisals, in particular stigmatisation of self (SS) would be associated with PLE severity and distress. It was not assumed, nor was it investigated, that primary and secondary appraisals in this group would be different to a community or clinical sample. Non-parametric correlational analyses partially supported the primary hypothesis in that an association was found between SS, PLE severity and distress. Regression analysis suggested that the association between stigma and PLE severity was independent of the common association with affective disturbance. Negative appraisals of PLEs and problems were associated with greater affective disturbance but not PLE severity.

It was also hypothesised that stigmatising attitudes towards mental health problems in others (SO) would be associated with appraisals, in particular SS. Again, it was not hypothesised that this group would hold greater SO than a community or clinical sample, nor was this tested. A correlation coefficient of a moderate to large size was found between SO and SS; however, while there was a trend towards significance, the relationship did not reach the stricter significance level set for secondary analyses. No association was found between SO and the other appraisals, or between SO and PLE severity. The relationship between SS and PLE severity was not affected by controlling for SO.

It was finally hypothesised that familiarity with mental health problems would be associated with SO, however no significant association was found.

A summary of key findings, their relationships to existing research and theory and implications for the hypothesised model, and for future clinical and research work is presented below.

4.2 Summary of findings

4.2.1 *Characteristics of the sample*

4.2.1.1 Demographics

The sample comprised just over twice as many boys as girls, replicating a recent large scale study of CAMHS use (Posserud & Lundervold, 2013). However, stigmatising beliefs were not associated with gender, suggesting that it is some other factor that makes access to services less likely for girls. The ethnic mix was representative of the local area in terms of the proportion of young people from a BME group (Office for National Statistics, 2012), although in such a small sample, full representation of all local groups is hard to achieve.

Half of the participants scored at or above the borderline range for self-reported emotional problems and/or overall problems. This is slightly higher than in studies of community samples (Goodman et al., 2000), as would be expected in a group of young people accessing services designed for emotional and behavioural difficulties occurring in the absence of a diagnosed mental health problem.

4.2.1.2 PLEs and distress

Over three quarters of the sample reported at least one PLE and over two thirds reported at least one in the past fortnight. More than half of the group reported distress or adverse impact associated with their PLEs. The study reflects previous findings that PLE severity is associated with current psychological distress (Barragan et al., 2011; Kline et al., 2012; Varghese et al., 2011). Again consistent with the service setting, rates of distressing PLEs, are slightly elevated compared to the general population (Laurens et al., 2011). However, the current findings are not directly comparable with a community sample due to differences in sample ages. It is not clear from the findings if this sample reports any more PLEs with any greater distress or impact than an equivalent sample in the community. The findings do show, however, that even in a group of clinically referred young people, many are experiencing PLEs without any adverse impact. This fits with previous research, which suggests that PLEs are common in young people (Laurens et al., 2012), particularly when they are psychometrically identified, as in this study. In the community, only a minority of PLEs are distressing; for most, they are low level and do not cause significant distress (Laurens et al., 2011) and these results suggest a similar pattern in this clinically-referred group. On measures of anxiety and depression, the group scored above the norms obtained in community samples, but average scores were not sufficiently high to classify the group as clinical.

4.2.1.3 Stigmatising beliefs

In the absence of a widely accepted, validated measure of either self-stigma or stigmatising beliefs about mental health problems, existing measures were adapted to be suitable to the present sample. These were evaluated in a focus group of young people in receipt of services and amended according to their feedback. The adapted measures of stigmatising beliefs were completed without difficulty by young people, and their internal reliability indicated that they functioned well as single scales.

All participants reported some stigmatising attitudes towards others with mental health problems, most frequently revealed in their attitudes towards segregation and their beliefs about the unpredictability of people with mental health problems. Since the measure is new and a community sample was not used in the present study, it is unclear whether this sample is any more or less stigmatising than the general population. There would not appear to be any reason to believe that this group would be more or less stigmatising about mental health problems than a community sample and should the measure be used in such a sample, it would be predicted that the descriptive statistics would be comparable. In terms of self-stigma, participants' mean average score fell between neutral and mild disagreement with self-stigma, a comparable finding to research on self-stigma in adults with clinical diagnoses (Brohan, Elgie, Sartorius & Thornicroft, 2010). This may indicate that young people presenting to CAMHS may already be conceptualising their difficulties in a way which leads them to self-stigmatise to a similar extent to those with diagnosed mental health problems, which may be contributing to levels of distress and impacting on social inclusion. As discussed above, it cannot be said that this group is more self-stigmatising than a community sample, however if a community sample scored similarly to both this sample and the clinical sample described by Brohan and colleagues (2010), this would lend further support to the assertion that self-stigma can be associated with PLEs in the absence of clinical diagnosis or even contact with services. Similar to previous research (Corrigan, Lurie et al., 2005), the majority of participants reported some level of contact with people with mental health problems, though most commonly the level of contact was low and indirect (i.e. through watching television rather than face to face contact with a person who has mental health problems).

4.2.1.4 Problem perceptions

Participants expressed most concern with the emotional impact of their problems. Appraisals of the timeline, consequences and control of problems are comparable to previous research of adults with clinical diagnosis of psychosis using longer versions of the IPQ but with a wider standard deviation (Freeman et al., 2012; Watson et al., 2006). Participants reported most

confidence in the level of treatment control over their problems, which also reflects findings from research of adults with psychosis (Lobban et al., 2005; Witteman et al., 2011). This may be partly explicable by this being a clinically-referred group, as beliefs about treatment control are implicated in treatment adherence (Lobban et al., 2005). While in this group the young person may not directly seek help themselves (as they may be brought to services by a carer), it is possible that young people who are avoidant of informing others in an effort to avoid contact with services would have different appraisals of their difficulties, in particular treatment control.

4.2.1.3 PLE appraisals

Participants who experienced PLEs reported on average that they were uncertain as to how external, personal and dangerous their experiences were. However, this masked a mix of responses, with just over half of young people making a negative appraisal on at least one dimension. Within the externality and agency domains, participants' responses were evenly spread between internal and external and between personal and situational. Within the danger domain, the majority of participants appraised their PLEs as at least "a bit dangerous". Again, this may be reflective of a group in contact with services but this cannot be certain without comparison with a matched community sample.

4.2.2 *Relationships between self-stigma, primary and secondary appraisals, PLE severity and distress*

4.2.2.1 Self-stigma

A significant, strong relationship was found between SS and PLE severity. A relationship between psychiatric symptom severity and SS has been found in adult studies (see Livingston & Boyd, 2010 for a review) but of interest in this study was the focus on an undiagnosed group of young people. As outlined earlier in this thesis, the presence of PLEs is not assumed to indicate a mental health problem by services, yet a clear relationship was observed between the severity of PLEs and the internalisation of stigma in this group. One possible explanation for this is that, although the young people in this group are not diagnosed with a mental health problem, greater severity of PLEs may mean that they display some of the 'markers', to use the term described by Sartorius and Schulze (2005), which singles them out and leads them to be categorised as a member of a stigmatised group. This then leads them to self-stigmatise, increasing the upset and impact associated with PLEs which in turn increases the likelihood of being stigmatised in what becomes a vicious cycle. While this relationship was demonstrated in a clinically-referred sample, there would be little reason to believe that it would be different for young people in the wider community. The only expected difference might be that, in the

community, the distress experienced by young people is not sufficient for them to present to services. Another possibility, since the SS measure referred to 'problems' rather than PLEs specifically, is that any SS recorded in the current sample is experienced on the basis of needing support from a CAMHS team and not specifically in relation to their PLEs. However, in spite of the fact that children are often brought to services by their caregivers and so have less choice about accessing services, the literature suggests that self-stigma potentially acts as a barrier to accessing services (Gulliver et al., 2010; Mojtabai, 2010; Mojtabai et al., 2011). This would imply that the process has usually already begun before attending services, rather than being triggered by needing a service. The young people in this sample were also approached while on the waiting list, meaning that many had no contact yet with services and the language used relating to services avoided insinuations of mental health problems as the young people may not have any. Therefore it would appear that the latter explanation is less likely.

A strong relationship was found between SS and affective disturbance on the depression measure, with greater SS being associated with lower mood scores. A weaker relationship which did not reach significance was observed between SS and anxiety. This suggests that self-stigmatisation is associated with negative affect associated with depression, such as feelings of loss, guilt, self-blame and sadness, rather than increasing perceptions of threat or vulnerability associated with anxiety. This finding reflects previous research on the effects of SS in adults with mental health problems (Livingston & Boyd, 2010; Markowitz, 1998; Rosenfield, 1997) but again this is the first time such a relationship has been demonstrated in young people with PLEs.

4.2.2.2 PLE appraisals

While a correlation coefficient of a medium size was observed between PLE appraisals and severity (with more external, personal and threatening appraisals being associated with greater PLE severity), it did not reach significance. This is unsurprising since appraisals were only measured in those reporting PLEs and so the correlational analysis was underpowered to detect a medium sized effect. PLE appraisals, were only significantly associated with anxiety scores and not with depression scores. The relationship between PLE appraisals and anxiety was strong, with more external, personal and threatening appraisals of PLEs being associated with greater anxiety. This may indicate that PLE appraisals act on affective disturbance in a different way to self-stigma in that they are associated with perceptions of increased threat and vulnerability characterised by anxiety rather than feelings of loss, shame and sadness in depression which appear to be more related to self-stigma.

4.2.2.3 Problem perceptions

No relationship was found between problem perceptions and PLE severity. This may reflect differences in the focus of their perceptions. As in adult research, the use of the term 'problem' leaves the respondent to decide on the problem to report, and young people may not have been responding in relation to PLEs, which may weaken the direct relationship between PLE severity and problem perceptions. However, a significant, moderate to strong relationship was found between problem perceptions and anxiety scores, with a trend towards significance for depression scores. More negative perceptions of the course and consequences of problems were associated with increased anxiety. This replicates the research in adults, and suggests that similar appraisal processes (perceiving problems as long-lasting and having a high impact) may be exacerbating problems through an affect pathway in young people.

4.2.3 *Relationships between SO and appraisals*

Secondary hypotheses were that SO would be associated with primary and secondary appraisals. While a correlation coefficient of a moderate to large size was found between SO and SS, such that greater SO was associated with increased SS, this only reached a trend towards significance. While previous research has measured associations between awareness of societal stigma and SS (e.g. Moses, 2009) or has measured stereotype agreement as part of SS (e.g. Watson et al., 2007), this is the first time that SO and SS have been measured separately in a group of young people with PLEs. Replication of the correlation size in a larger sample or as the primary analysis would be required to draw stronger conclusions about the relationship between SS and SO. No significant relationships were found between SO and PLE appraisals or problem perceptions, suggesting that the hypothesised pathway, whereby views of mental health problems in others impact on PLEs via the development of self-stigmatising beliefs and other negative appraisals, is incorrect. Rather, SO appeared to impact solely on SS, and SS in turn on other secondary appraisals, PLE severity and distress.

4.2.4 *Relationship between familiarity and SO*

Finally, the hypothesised relationship between familiarity with mental health problems and SO was not found in this study. A weak to medium correlation size was observed with greater familiarity with mental health problems correlating with lower SO, but this did not reach significance. As the primary analysis was powered on an assumed strong relationship of r= 0.5, it is possible that the study was underpowered to detect significance with a weaker relationship. It should also be noted that the measure used does not enquire as to the quality of contact with people with mental health problems. It is suggested that the conditions of the contact may influence how stigma is affected (Corrigan, River et al., 2001; Couture & Penn,

2003) and it is not recorded whether the contact was with someone who mildly contradicted stereotypes of mental health problems, for example. Also, the score given for level of familiarity is based on the highest single level of contact. Therefore someone who has watched several information programmes on mental health and met people with mental health problems and knows children in their class with mental health problems will still score lower than someone who has a family member with a mental health problem, even if it is not spoken about or is heavily stigmatised by other members of the family. The findings of the present study may support the assertion that the qualitative aspects of the contact play a greater part in the reduction of SO than simply the level of contact, although an effect of level of contact has been found in previous research regardless of assessment of quality (Corrigan, Lurie et al., 2005).

4.2.5 *Post hoc analyses: predictive power and independence of SS on PLE severity*

A trend towards significance was found in the correlation between SS and problem perceptions. This may indicate that those participants with higher levels of SS tended to hold more pessimistic views about the course, impact and consequences of their problems; however, as the size of the correlation was smaller, replication with larger numbers would be required before the null hypothesis can be fully rejected. No relationship was found between SS and primary appraisals of PLEs.

The relationship between SS and PLE severity was not accounted for by SO. This would suggest that, while SO is potentially associated with SS, it is not a key process in the relationship between SS and PLE severity. Almost half of the variance in PLE severity was accounted for by self-stigmatising beliefs and negative affect, and that SS was the only significant contributor to the model when the other two variables were controlled for. However, the high level of correlation between depression and SS scores indicates that multicollinearity may be biasing the model and so it should be interpreted with caution.

4.3 Limitations of the research

4.3.1 *Study design*

The first limitation of this research in terms of design was the small numbers involved. The study was sufficiently powered to detect a moderate to strong relationship in the primary hypothesis as intended; however it was underpowered to detect weaker relationships which may still have been significant with greater numbers, such as the relationships between PLE appraisals and severity, between self-stigma and anxiety or between familiarity and the stigmatisation of others. While relationships of interest were suggested by the size of the

correlation, the null hypothesis could not be rejected for any of these relationships. The small number involved also limited the use of regression analyses, as the recommended cases of data per predictor model suggested by Field (2005) limited the number of predictor variables in the model to three.

The second design limitation relates to the correlational design of the study. It should be noted that, while causal relationships are suggested in the literature relating to the associations between types of stigma, appraisals and PLE severity, the current study is a cross-sectional and correlational design from which causation in any of the relationships studied cannot be inferred. Directions of relationships are hypothesised below but causal associations would need to be tested using longitudinal or experimental designs in which individual variables can be tracked over time or manipulated to assess the effects on related variables.

Because the young people in the current study were not diagnosed with any mental health problem, presenting problems were not recorded. This has implications for the interpretation of results as it was not possible to compare, for example, if the relationships observed differed depending on presenting problems such as internalising or externalising problems. In a longitudinal study (see Section 4.4.5) a diagnostic follow-up would allow for such a comparison but as the present sample was taken from the waiting list and undiagnosed, it was not possible to record this in the present study.

4.3.2 *Measures*

4.3.2.1 Stigma measures

In order to ensure that measures were phrased appropriately and suitable in length for the population being investigated, this study utilised measures of stigma which had been adapted from their existing, partially validated forms. The rationale for this was that a number of well validated measures of both stigmatising attitudes towards mental health and self-stigma existed for adults but their development for children remained in its early stages. It could be considered a limitation that well researched and validated, child-oriented measures were not available to measure the stigma variables in this group; however efforts were made to ensure that the measures used tapped areas of SO and SS assessed by existing measures by using similar formats and questions and the amendments made were either suggested or approved by a focus group of young people already in receipt of mental health services (see Section 2.3). The measures also demonstrated satisfactory internal consistency and so it is believed that these measures, although not fully validated themselves in young people, still represent an appropriate measurement of SO and SS in the sample given the limited availability of

alternatives at the time of measurement selection. The further adaptation and validation of these measures in future research into stigma and self-stigma in young people will ensure that robust, validated questionnaires will be more readily available.

4.3.2.2 PLE appraisals

Appraisals of the externality, agency and dangerousness of PLEs were measured by adding items to the PLE measure in the same questionnaire style. This differs from previous research in adults which has enquired about appraisals through interview methods (Brett et al., 2007). This method of measuring appraisals has not therefore been validated in young people. However, the dimensions and scoring principles were the same, and a good range of scores was obtained. Furthermore, although failing to reach significance, the association between appraisals and PLE severity was moderate, and in the expected direction. This suggests that the measure has promise and has the advantage of being considerably shorter than the interview method. Nevertheless, using a self-report questionnaire may miss an important aspect of interpretation and relies on the young person understanding the potentially confusing concepts of externality and agency although these were, of course, expressed in child-friendly language and road-tested by a group of young people. It remains possible that the lack of an association between appraisals and PLE severity in this study is due to the different methodology, although the lack of power is also a strong candidate explanation.

4.3.3 *Generalisability*

The participants taking part in the present study were of various ages and there was some variation in ethnicity. However, they were all between the ages of 8 and 14 years and lived in London boroughs. As is a common limitation in such research, the findings may not be generalisable to older or younger children from other areas of the country and would require replication in different groups.

4.4 Implications of findings

4.4.1 *Pathways of action of stigma and appraisals on PLE severity*

The original hypothesised model, based on a review of the existing literature, proposed that the severity of PLEs and affective disturbance would be affected by stigma and appraisals. Both primary and secondary appraisals were hypothesised to directly affect both PLE severity and affective disturbance.

The present findings partially support this model, though the direction of relationships requires further investigation. All three types of appraisal were moderately to strongly

associated with affect, either on anxiety or depression measures. The different associations raise the possibility of different routes mediating threat and loss reactions and potentially interesting inter-relationships between appraisals. Self-stigma, but not the other two appraisals, also had a direct relationship with PLE severity, irrespective of its association with affect. This influence did not appear to operate through the appraisal of the PLE, although this finding should be treated with caution in light of small sample size, and our findings cannot be considered to refute the hypothesised associations, merely not to support them. A proposed model of the interrelationships between PLEs and primary and secondary appraisals can be seen in Figure 4.1.

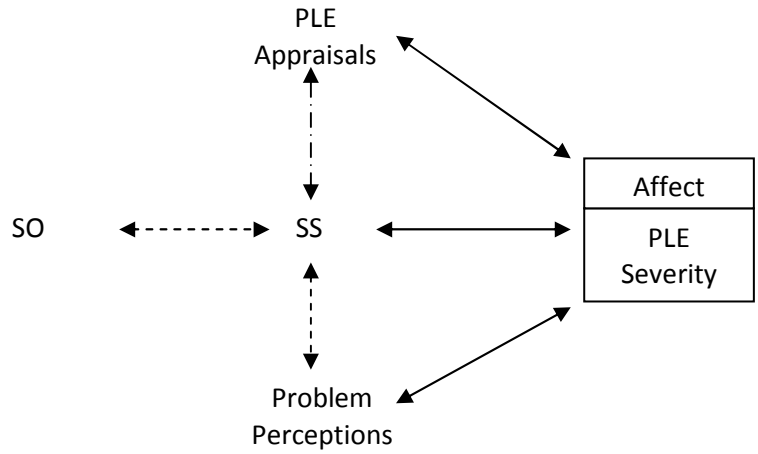

Figure 4.1: Proposed model of interactions between PLEs and primary and secondary appraisals (SO= stigmatisation of others; SS= self-stigma; PLE= psychotic-like experiences)

→ Relationship fully or partially supported - - - → Trend towards significance – · – → Not found but still hypothesised

4.4.2 *Implications for stigma theory*

The above model suggests that SO is relevant to the development of SS but does not influence PLE severity, appraisals or affective disturbance; nor does it influence the relationship between SS and PLE severity. SS may influence PLE severity directly or via affective disturbances and affective disturbance is associated with PLE appraisals. Proposed relationships between PLE appraisals and SS and PLE severity and between problem perceptions and PLE severity were not refuted in the present study but were not sufficiently supported to reject the null hypothesis. Associations between SO and SS and between SS and problem perceptions reached a trend towards significance but did not reach the stricter alpha level set for this study. These result are therefore of interest and warrant further investigation in a larger sample or as the primary analysis but a relationship cannot be fully asserted based on the current findings.

It was expected that SO might have a direct effect on problem perceptions or PLE appraisals if the beliefs which young people held about mental health problems affected their own experience of problems leading to service use. The results did not support this assertion and presently it appears that SO only acts on SS in the way theorised above and does not directly affect primary or secondary appraisals of PLEs or other problems requiring involvement of CAMHS. Participants' actual experience of discrimination was not measured, so previous findings on the impact of stigma on those experiencing mental health problems are not commented on here.

Corrigan and Watson's (2002) social psychological model of the internalisation of stigma holds that stereotype agreement is necessary but not sufficient for stigma to become internalised and to subsequently impact self-esteem and self-efficacy. Stereotype agreement is one aspect of SO measured in this study and it would be expected that in instances where there is high stereotype agreement there would be similar attitudinal and behavioural responses in keeping with a stigmatising approach. The results of the present study suggest that high SO may be associated with high SS, which would lend support to Corrigan and Watson's (2002) assertion that it forms part of the self-stigmatising process. However, their model suggests that SO is primary, which the present study cannot comment on due to its cross-sectional design. Corrigan and Watson's (2002) model also suggests that SS will impact on self-esteem and self-efficacy. While these outcomes were not specifically measured, it was notable that SS correlated more strongly with depression scores than with anxiety scores. This might be expected if SS were acting on self-esteem. The observation that SO did not significantly influence the relationship between SS and PLE severity may also fit with Corrigan and Watson's (2002) model. It may be that high stereotype agreement (which is one aspect of SO measured in the present study) would be associated with high SS but that, in the context of PLE severity, processes such as perceived legitimacy, self-concurrence or affective processes such as those posited by Ben-Zeev and colleagues (2012) are more important in influencing the relationship between PLE severity and self-stigma.

4.4.3 *Implications for PLE and psychosis theory*

The results of the present study reflected previous findings regarding the commonality of PLEs in young people. The proportions of children and young people experiencing PLEs and reporting both significant upset and impact as a result of PLEs are slightly higher than in research by Laurens and colleagues (2011), which used the same method of measurement of PLEs. However their sample was in the community whereas the present sample was clinically referred. It may be that the prevalence of PLEs, and in particular upsetting and impacting PLEs,

would be expected to be higher in groups experiencing sufficient distress to access services, however the sample in the present study is too small to make firmer statements about whether the prevalence or severity of PLEs in a clinically referred sample is any different to a community sample. Nonetheless, the picture of the distribution of PLEs within the sample is consistent with findings from previous research, with scores on PLE severity clustered towards the lower end of the spectrum and fewer participants reporting high PLE severity.

The study contributes novel findings to the understanding of the role of secondary appraisals in children and young people with PLEs. Self-stigma has a strong association with PLE severity which is not accounted for by its correlation with stigmatising beliefs about mental health problems and may be independent of its association with affective disturbance. Analysis of the relationship between PLE appraisals and PLE severity suggested a weak correlation which did not reach significance and was underpowered. The results, combined with the existing literature, suggest that appraisals are an important factor in the severity of PLEs, whether they act directly on PLEs or through affect. Placing the findings within the context of cognitive models of psychosis, this study tentatively suggests a similar pattern to existing models where an initial trigger leads to an unusual experience. The interpretation and appraisals of the experience then drive emotional responses to the experiences. The findings are suggestive of a similar process to current theoretical models.

This study was not designed to directly address the debate over continuum models of psychosis. As described in Section 1.2.2, the current study approached PLEs endorsing a continuum perspective since this would be supported by the cognitive model. The findings of a skewed distribution of PLE severity with many experiencing at least one, a substantial proportion experiencing two or more and a smaller proportion experiencing upset, impact or both as a result would appear to support such a continuum, however assertions in the literature that there may be qualitative differences between types of PLEs or levels of need for care were not addressed as they did not form part of the hypotheses. Sommer (2010) claims that there may be differences in the quality of experiences between those with and without clinical disorders. Since the present study assessed PLEs and not psychosis, comparisons cannot be made between clinical and non-clinical groups. Kaymaz and van Os (2010) suggest that further research is required to compare PLEs in people with and without the need for care and Preti and colleagues (2012) propose a pyramid model in which people with PLEs are split according to appraisals and distress. While the correlation between appraisals and distress suggests a relationship which may fit with Preti and colleagues' (2012) model, categorical distinctions are not applied in this study and the study was not designed to compare

categorical groups. Similarly, since the study only recruited young people accessing services, there was no scope to compare young people with and without the need for care as suggested by Kaymaz and van Os (2010) and by Nelson and Yung's (2009) categorical distinctions of young people with PLEs. Extensions of the present study which may help to address these points and illuminate the continuum debate are described in Section 4.4.5.

4.4.4 *Implications for supporting young people with PLEs*

The present study has implications for how PLEs are approached clinically in children and young people who experience significant distress or impact as a result. According to cognitive models of psychosis, psychological processes (including primary and secondary appraisals of experiences) are the key intervention targets in reducing positive symptoms and distress (Garety et al., 2001). Previous research findings that similar psychological processes may drive PLE persistence and severity (Arseneault et al., 2011; Fisher et al., in press; Kelleher et al., 2008; Morgan et al., 2009) and current findings that primary and secondary appraisals are associated with PLE severity and distress would suggest that the same is true for the treatment of distressing PLEs. Preliminary research has highlighted the potential utility of cognitive interventions in reducing distress (Maddox et al., 2013) and the present study supports further investigation into the efficacy of cognitive therapy for distressing PLEs in young people. This research has also suggested that, since the extent to which young people self-stigmatise is associated with the severity of PLEs and distress, interventions at this stage could be specifically targeted to help to de-stigmatise PLEs, which may reduce distress and even PLE severity. This study therefore contributes to the development of cognitive therapy for distressing PLEs. Since most young people who experience PLEs will not go on to develop psychosis, it could be argued that such intervention is not necessary; however the current findings suggest that interventions even in the absence of clinical diagnoses is warranted to address the distress associated with PLEs rather than to reduce the risk of future psychosis. This assertion is supported by the latest guidance that treatment of children and young people with PLEs should be psychological rather than pharmacological (NICE, 2013).

Addressing self-stigma also has implications for young people accessing services. Previous research has suggested that experience of stigma may reduce help-seeking in young people with mental health difficulties (Burns et al., 2009; Chandra & Minkovitz, 2007; Gulliver et al., 2010). Therefore addressing self-stigma may be important for improving engagement with services and improving problem perceptions.

The findings of the present study do not suggest that the severity of, or distress caused by, PLEs is necessarily greater in clinically-referred young people than in the general population. Nor do the findings suggest that this sample is more self-stigmatising than young people in the general population, as a community sample for comparison would be required to test this. Nonetheless, the observed relationship between SS and PLE severity and distress suggests that, in young people presenting to services and in whom distressing PLEs should be treated according to the latest guidelines (NICE 2013), the severity and distress of PLEs will be associated with the amount to which the young person self-stigmatises. This therefore highlights the importance of stigma in the treatment of distressing PLEs regardless of whether the present sample differs from a community sample.

Cognitive models provide a target for intervention in the event of distressing PLEs, however the trend towards significance in the correlation between SO and SS, when combined with existing literature on stigma interventions, may indicate a pre-emptive intervention opportunity that serves not only to reduce the stigma of mental health problems and its effect on those who experience them but also possibly to reduce the impact of SS in the event of PLEs. While the present study cannot firmly claim such an intervention would result in these outcomes, the evidence is sufficient to warrant further investigation. A worldwide anti-stigma campaign has implemented educational and anti-stigma interventions in a variety of settings (Sartorius & Schulze, 2005) including secondary schools (Pinfold et al., 2003) with promising results. These interventions have been aimed at reducing stigma and discrimination of mental health problems in an effort to reduce the negative consequences for those who experience them. Given the emerging evidence of the effectiveness of school based anti-stigma interventions (Pinfold et al., 2003; Watson et al., 2004), the evidence from adult studies in other settings (e.g. Munoz, Sanz, Perez-Santos & de los Angeles Quiroga, 2011) and the trend observed in the present study, it may be that educational workshops for school children could help reduce SO which may in turn reduce SS. If this were the case, it could have implications for the level of distress experienced by children and young people with PLEs. This research would therefore support further investigation into the use of educational workshops delivered in schools to help reduce stigma and potentially the distress experienced by the large proportion of young people who will experience PLEs. A recent public campaign, Time to Change, spearheaded by mental health charity Mind, has shown promise in improving public attitudes and behaviours towards people with mental health problems (Evans-Lacko, Malcolm et al., 2013; Henderson et al., 2013; Thornicroft et al., 2013). However, research suggests that people with psychosis may be more vulnerable to stigma (Crisp et al., 2000; Jorm et al., 2012; Yap et al., 2013) and more specific educational campaigns, targeting psychosis and tailored to

the needs of young people, may therefore be required in order to address this. Organisations such as The Voice Collective or the Hearing Voices Network may provide opportunities to develop a de-stigmatised understanding of PLEs or psychosis but such initiatives are aimed at those experiencing PLEs, and particularly voices, rather than the wider public.

4.4.5 *Future research*

In order to apply the findings of the current study to groups of different ages or locations, the study would need to be replicated in different groups. The small numbers used in the study also mean that replication in larger numbers, particularly in the correlations which showed trends towards significance or were underpowered, is necessary for firmer conclusions to be drawn about those relationships. Given that stigmatising attitudes are shown to have potentially developed at a younger age than the current sample (Scheff, 1963; Weiss, 1986, 1994), further research with a younger group may help to elaborate how stigma develops.

The cross-sectional relationships demonstrated in this study justify further investigation in a larger, longitudinal study. Previous research has highlighted the fluctuating nature of appraisals of psychotic experiences and level of SS according to affect and circumstances (Ben-Zeev et al., 2012; Brett et al., 2007). A longitudinal approach could track changes in these variables to observe whether they co-vary over time. Similarly, assessment of community samples would allow a longitudinal follow-up of how SO in young people without PLEs affects their appraisals if they do develop them later on. This may then lend more support to the assertion that SO precedes SS with the above model. The inclusion of a community sample would also provide opportunities to compare groups with and without PLEs or those with PLEs with and without distress or the need for services. One way in which this could be achieved is through the use of assessment of children at schools at appropriate intervals (e.g. annually or biannually). Using similar questionnaire methods, long term shifts in stigma, affect and PLEs could be monitored. In particular, where young people develop PLEs during the course of the study, pre-existing stigma beliefs could be compared with PLE severity and appraisals, which could both be compared with distress. Such research would help to establish whether stigma beliefs are in fact primary and self-stigma arises subsequently with the development of PLEs

Experimental methods which are able to isolate and manipulate variables such as stigma or secondary appraisals would further help to establish causation within the model and provide further evidence for useful targets of cognitive therapy in young people with distressing PLEs. For example specific educational workshops on PLEs, in particular normalising these and distinguishing them from clinical diagnoses, may lead to an observable difference in stigma

beliefs in those without PLEs or both stigma and self-stigma in those with PLEs. Subsequent changes in distress or other secondary appraisals could then be attributed to changes in stigma.

The participants in this study, by definition, are experiencing some difficulty requiring presentation to services. Nelson and Yung's (2009) proposed third group of young people with PLEs (with no clinical problems and in whom PLEs confer no increased vulnerability) are much less likely to feature in this sample. The sample is mostly likely made up of young people experiencing PLEs as part of an underlying disturbance or as epiphenomenal to other problems for which they are seeking help. The latter two groups were not separated in this study, which would have required some form of diagnostic follow-up. Future research could address alternatives to the continuum model by comparing groups without CAMHS input and how they differ in terms of appraisals, PLE severity and stigma.

4.5 Conclusions

The results lend support to the extension of cognitive models of psychosis to those with PLEs, in that psychological processes, particularly self-stigma, appear to interact with the severity of PLEs and affective disturbance. This was the first time these factors have been investigated together in this group. The findings have implications for the understanding of PLEs in young people and how children and young people with distressing PLEs can and should be supported even in the absence of a clinical diagnosis. The present study fits with the current guidance that cognitive interventions should be the primary form of intervention for young people with distressing PLEs, as they are likely to be more supportive than medication.

While the study is cross-sectional and correlational in its design, it contributes to existing research and theory on both the stigmatisation of others with mental health problems and the internalisation of stigma. In particular it adds to the relatively limited research of stigma and SS in young people. It also contributes usefully to research on PLEs in young people and highlights areas of possible intervention, not only for those with distressing PLEs but also to potentially mitigate against the damaging effects of self-stigma in children and young people. Findings also demonstrated that models of stigma development may be applicable very early on in the development of difficulties in young people. Public health interventions such as the Time to Change programme may therefore benefit from being extended into schools and to more specifically address PLEs and psychosis. The targeting of such interventions at a younger population in combination with a national campaign aimed at adults may reduce the need for national anti-stigma campaigns for future generations, as young people are less influenced by

stigmatising attitudes and in turn exhibit fewer stigmatising attitudes and behaviours as they grow up, thereby reducing the opportunity for future generations to socially learn such attitudes.

As severity and persistence of PLEs are associated with both current adverse impact and future mental health problems, stigmatising appraisals may form a new and important treatment target. Identifying causal relationships to guide the targeting of interventions will require further longitudinal research and building an evidence base of intervention strategies will require experimental research. The present research highlights the importance of addressing stigma at an early stage in children's development, not just for the benefit of other people with mental health problems but also for the benefit of those children who develop mental health problems later in life.

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6. APPENDICES

Appendix 1: Ethical and R&D approval for CUES amendment

NHS
Health Research Authority

NRES Committee London - Hampstead
Northwick Park Hospital REC Centre
Level 7, Maternity Block
Northwick Park Hospital
Watford Road
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Tel: 020 8869 2915
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05 December 2011

Dr. Suzanne Jolley
Research Clinical Psychologist
Kings College London, Institute of Psychiatry
PO77 Department of Psychology
IOP, 16, De Crespigny Park,
Denmark Hill,
London SE5 8AF

Dear Dr. Jolley

Study title:	**Coping with unusual experiences and emotional problems: an evaluation of a training package for children aged 8-14 years.**
REC reference:	**11/LO/0023**
Amendment number:	**Amendment 1**
Amendment date:	**27 November 2011**

The above amendment was reviewed at the meeting of the Sub-Committee held on 30 November 2011.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
The Brief COPE scale		
Warwick-Edinburgh Mental Well-Being Scale		
5-minute speech sample (Magana et al., 1986)		
Hospital Anxiety and Depression scale		
Revised PLE measure	2	12 November 2011
Questionnaire: The Brief Illness Perception Questionnaire (Child)	1	15 October 2011
Questionnaire: Social support questionnaire	1	15 October 2011
Participant Consent Form: Carer	3, highlighted changes	20 November 2011
Participant Information Sheet: Carer	3, highlighted changes	20 November 2011
Protocol	2	20 November 2011
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	27 November 2011
Covering Letter	from Dr Suzanne Jolley	20 November 2011

Familiarity with mental health problems	1	12 November 2011
Stigma measure (Ritscher et al., 2003)		
Stigma vignette	1	12 November 2011
Questionnaire: The Brief Illness Perception Questionnaire (Parent)	1	15 October 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/LO/0023:	**Please quote this number on all correspondence**

Yours sincerely

pp Abhayani

Dr Michael Pegg
Chair

E-mail: alkabhayani@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to:

Ms Jenny Liebscher
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Dr Suzanne Jolley
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15 December 2011

Study Title: Coping with unusual experiences and emotional problems: an evaluation of a training package for children ages 8-14 years
R&D approval number: R&D2011/028
Amendment number and date: 1 – 27/11/2011

Dear Dr Jolley

I am writing to confirm that the above project amendment has received R&D approval and the changes have been noted in our records.

With best wishes

Sally Moore
R&D Administrator

Appendix 2: Summarised clinical operating protocol for CUES

Institute of Psychiatry

at The Maudsley

South London and Maudsley NHS
NHS Foundation Trust

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Coping with Unusual Experiences for Children Study (CUES)
Summarised Clinical Operating Protocol

Referrals: The research team to have access to all eligible referrals (children aged between 8-14 and not requiring urgent intervention) who have been placed on the waiting list within the CAMHS Tier 2 services. Each referral will be sent a letter and reply slip inviting them to participate in the study. The letter will include information sheets and consent/assent forms for both parents/carers and the child. This letter will state that a research worker will contact them unless they specify otherwise. All contact will be recorded in the young person's notes.

Outcome of first contact: Three possible outcomes from first contact:

1. Reply slip indicating interest- in this case, the research worker will contact them to arrange a meeting to discuss the project in more detail.
2. Reply slip indicating desire not to be contacted-the research team will not contact them again, and this will be noted on the young person's record.
3. No response- research team will provide a follow-up phone call to explain the project and find out if they would like to participate. If yes, a meeting will be arranged.

If any form of risk or new information becomes apparent during the referral process, the clinical team will be informed immediately so appropriate action can be taken. If immediate action is required and member of the clinical team can not undertake this, a member of the research team will contact emergency services, having discussed this with a clinician if possible.

First meetings & informed consent: A member of the research team will meet with the young person and parents/carers to go through the information sheets on the study. This should take about 15 minutes. They will have the opportunity to ask any questions they may have about the study. Consent will then be obtained if they wish to take part. There will be at least 24 hours between receiving information about the study and commencing assessments. All contact will be recorded in the young person's notes.

Notification of taking part in the study: When a family consent to participating in the study the CAMHS leader will be notified by letter. Subsequently, their GP will be informed of their participation and any other relevant services will be informed if the family consent to this.

Assessment & therapy: Parents and children will complete questionnaire measures. A brief report on baseline assessments will be given to the family, clinical team and GP. If the child reports unusual experiences and emotional problems, they will be offered the therapy, either straight away or after 3 months. Baseline assessments, full CAMHS assessments, child brief risk screen and the CGAS will be completed in the first therapy session.

Tier 2 intervention: If the young person reaches the top of the Tier 2 waiting list whilst taking part in the study, their Tier 2 care should continue as normal. If the young person completes their Tier 2 intervention whilst still taking part in the study, their case will remain open until the follow-up assessments for the study have been completed.

Dropout: Participants can leave the study at any point should they wish, without giving a reason. Their treatment and care from other services will not be affected.

End of study: Findings will be presented to clinical teams. However, this study is not part of routine services, so it is not guaranteed that the intervention will be available after the completion of the study.

Appendix 3: Recruitment letter

Institute of Psychiatry

at The Maudsley

South London and Maudsley NHS
NHS Foundation Trust

Dr. Suzanne Jolley PO77
Department of Psychology
Institute of Psychiatry
De Crespigny Park
Denmark Hill
London SE5 8AF

Tel +44 (0) 20 7848 5028
Fax +44 (0) 20 7848 5006
Email :
suzanne.jolley@kcl.ac.uk

KING'S College LONDON Founded 1829

University of London

Date

Address

Dear xxxx,

We are writing to everybody who is referred to Child and Adolescent Mental Health Services to ask if they would like to take part in a research study. We are contacting everybody in this way to make sure we do not miss anybody out. It is entirely up to you whether you decide to take part, and this will not affect the care you receive from the service you have been referred to in any way.

With this letter, we have sent some information sheets that describe the study and what it will involve. There is a sheet for you, as parent or carer, and two short sheets for your children in case they would like to know more.

If you are not interested, or would prefer not to take part, please just ignore or destroy the letter and the sheets. If you would like to find out more about the study, or think you might like to take part, please contact us on xxx xxxx xxxx.

A researcher from the study will try to call you in a week or so, to check if you have received the letter and whether you would like to find out more or to take part.
You do not have to speak to the researcher, and if you would prefer them not to call you, please let us know on xxx xxxx xxxx.

Thank you for your time.

With best wishes,

Jonathan Bradley
Researcher

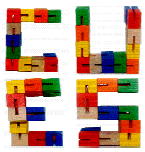
Enc. Information sheet for carers
Information sheet for young person

Appendix 4: Information sheet for parents or carers

South London and Maudsley NHS
NHS Foundation Trust

Dr. Suzanne Jolley
Research Clin
Psychologist
PO77 Department
Psychology
Institute of Psychiatry

KING'S College LONDON
University of London



Information Sheet for Parents/Carers
Version 2 – 10/4/11

Title of study: Coping with Unusual Experiences (CUES)

We are inviting you and your child to take part in a research project.

You should only take part if you want to.

If you do not want to take part, this will not affect the usual care or services that you or your child receives in any way.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully.
One of our team will go through the information sheet with you and answer any questions you have. This should take about 15 minutes.
Talk to other people about the project if you want to.

- Part 1 tells you the purpose of this project and what will happen to you if you take part.

- Part 2 gives you more detailed information about how the project will be carried out.

Please ask us if there is anything that is not clear or if you would like more information.

Contact details: Nedah Hassanali (Research Worker): Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF. Tel no: 0207 848 5794/ 07427475940

Karen Bracegirdle (Research Therapist): South London and Maudsley NHS Foundation Trust, Southwark CAMHS, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411

REC Reference Number: R&D2011/028

You will be given a copy of this information sheet

Part 1

What is the purpose of the project? We are trying to find new ways to help children cope with unusual experiences, emotional problems and stress. We have put together a package of strategies, which we hope will be helpful. We talk young people through the package to help them learn new ways of coping with their problems. The package is based on talking therapies which have been shown to be helpful for both adults and children reporting anxiety or worries, low mood and unusual experiences. Some children have already completed the package, and they said they liked it and found it helpful. The next step is for more children to complete the package and for us to find out how they feel and how they are coping before and after completing the package, and to compare this to children who have not completed the package.

We also want to find out more about the causes of upsetting unusual experiences in young people, so we will be asking all the children who agree to take part in the study, and their parents or carers, to answer some questions about feelings and experiences, and complete some activities about everyday problems and situations. We will then compare a group of children with unusual experiences who feel upset to children who do not have these experiences.

What do you mean by 'unusual experiences'? Lots of people have experiences which can seem unusual to others. For example, hearing voices that other people cannot hear, seeing, feeling or smelling things that other people cannot, or finding that things around them look somehow odd or different. These experiences are much more common than most people think and often do not cause any problems for the people experiencing them. They might even be enjoyable. However, sometimes these experiences can be upsetting or worrying to the person who has them, or can stop the person doing what they normally do. This in turn can interfere with school or work, friendships and family relationships. There are some strategies for dealing with both the experiences and the upset that can happen alongside them. The package is a collection of these strategies, and we would like to find out whether it helps young people to cope.

Why has my child been asked to take part? We are offering the package to children aged 8-14 who are seeking help from Child and Adolescent Mental Health Services. For the first part of this study, we are inviting all children in the service and their parents/carers to complete two questionnaires which ask about unusual experiences and feelings. This is to find out if the package will suit your child. Your child will need to be able to speak enough English to understand the package and the questionnaires. For the second part of the study, we will offer the package to children who report an unusual experience and feeling upset. We will also ask some children who do not report an unusual experience and feeling upset to complete some questionnaires and activities.

What will my child and I be asked to do?

Stage 1: If you and your child would like to take part in the study, you will first need to sign the form at the end of this sheet, to say that you are happy to go ahead. In the first stage of the study, your child will complete the two questionnaires to see if the package is suitable. These will take about 15 minutes to complete, in a short meeting with a research worker. If the package is suitable for your child, he or she will be invited to take part in the second stage of the study.

If the package is not suitable for your child (because he or she is not having unusual experiences or feeling upset), we will ask you and your child to complete some questionnaires about feelings and experiences, and complete some activities designed to show how people think about everyday problems and situations so we can find out more about what causes unusual experiences and upset. This will usually take two or three meetings or about two hours in total, with the research worker, and can be spaced over as many meetings as you like.

Stage 2: In the second stage of the study, half of the children taking part will be invited to complete the package immediately, and half will be asked to wait for 3 months before completing the package. This is so that we can see if adding the package is more helpful than just waiting for help from Child and Adolescent Mental Health Services.

To see if the package is more helpful than just waiting, it is important that the group of children who receive the package straight away and the group who have to wait for 3 months are as similar as possible. Whether your child receives the package straight away or after a wait will therefore be decided by chance (randomly), by a process a bit like tossing a coin. This will be carried out at a centre separate to the research team, who will not have any information about you or your child. You will not be able to choose which group you and your child are in, nor will any member of the team.

Completing the package will involve your child attending some meetings with a therapist. There will usually be around 9-12 meetings lasting about 45 minutes each, but we can arrange the number and length to suit your child. The meetings will usually take place weekly for between two to three months. They will be held at a location to suit you and your child. We will try hard to make appointment times convenient for you and your child. For example, wherever possible appointments will be made outside of school hours.

As a way of checking that the therapists and research workers are all working in the same way, and working with the package as well as possible, we would like to audiorecord the meetings. You and your child will be asked whether this is OK each time they meet with the therapist or researcher.

You and your child will be asked to complete some questionnaires and activities at the very start of the study, after completing the package or after the 3-month wait, and again after one month, so we can see if any positive changes last after the package has been completed. The questionnaires and activities are to see whether the package is helping your child or not. This usually takes two or three meetings with a researcher, or about two hours in total. Your child will also be asked how they found the package and any changes they would suggest for the future. We will also ask you for feedback on how you have found things while your child has been attending the meetings.

Your child will be given a £5 gift voucher as a thank-you for taking part in the project.

Will my and my child's taking part in the study be kept confidential? The information you and your child give us will usually be available only to the research team. However, the researcher will share with your clinical team any important information that is relevant to the care you receive, and will let the team and your GP know that you are taking part in the study, and will note down on the team's notes system that you are taking part in the study and when they meet with you. If you or child tell us anything about someone being hurt or not safe, we will have to tell other people who are there to help with these kinds of situations. More details are included in Part 2.

How will the information we give you be kept? All the answers you and your child give to the questionnaires and activities will be kept on paper and as an electronic file. The recordings will be kept as electronic files. They will be kept securely and anonymously and will be identified only by a number, not by your name. Your name will be kept separately, with the number, on paper, so that we can identify your questionnaires and recordings in the future if we need to (for example, if you decide you no longer want to be part of the study). We will only identify your questionnaires for a reason like this. Your details will be kept for up to 12 years, and then will be confidentially destroyed. We will keep a completely anonymous copy of the electronic file indefinitely, from which you will not be able to be identified at all. At the very end of the study, once we have seen a number of children, you and your child will be given a summary of the results.

Is there any risk from taking part? We do not think that the package will be harmful in any way. We want it to be helpful and it has been designed to be fun. The questionnaires and activities are all either designed for children and their parents or carers, or especially adapted for children, and have been approved by researchers who have many years experience of working with children. However if you or your child are distressed in any way by taking part, the therapists working on the study are qualified to deal with this sensitively and appropriately. If this happens, please talk to the researcher, or to one of the therapists. (Nedah Hassanali -Research Worker: Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF, Tel no: 0207 848 5794/ 07427475940 or Karen Bracegirdle (Research Therapist): 1st Floor Mapother House, De Crespigny Park,
London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411).

Are there any benefits of taking part? We hope that the children will enjoy taking part in the study and will learn some useful strategies for coping with day to day stresses. Both children and adults also sometimes find completing the questionnaires interesting and helpful.

Do I have to take part?
It is up to you and your child to decide whether or not to take part in this study. If you do decide to take part you are still free to stop at any time and without giving any reasons. This will not affect any other help or support that you or your child will be offered.

What happens when the project stops?
When you have finished taking part in the research, you will carry on as usual seeing the team where you were originally looking for help. If this help is available before the project finishes, you will be able to still carry on with the project if you would like to. We will ask you and your child if you would be willing to be contacted regarding future projects, and if you would, we will keep your name and contact details. You will be able to ask us not to contact you at any time, and this will not affect you in any other way. This project is only running for three years from 2011, and we cannot guarantee that the package will still be available after this.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are thinking about taking part, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

What if relevant new information becomes available? Sometimes we get new information during a project. If we find out anything new about any of the questionnaires or the package which means it might be harmful or upsetting for you or your child in any way, we will tell you both at once and you can decide whether or not you want to carry on.

What will happen if I, or my child, no longer want to carry on with the study? If you decide you no longer want to take part, you should let us know at once. A member of the research team will talk to you about which parts you no longer want to be involved in (for example, you might not want to come for the package, but feel OK with the questionnaires). We would like to still keep the information you have already given us if this is possible, but we will check this with you as well. You can tell us that you would like us not to keep any information at all about you, and in this case we will destroy all our copies of the information you have given us. This will not affect any other care you or your child might be offered, or your rights in any other way.

Complaints: If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. (Nedah Hassanali -Research Worker: Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF, Tel no: 0207 848 5794/ 07427475940 or Karen Bracegirdle (Research Therapist): South London and Maudsley NHS Foundation Trust, Southwark Targeted CAMHS, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (PALS, The Maudsley Hospital, Denmark Hill, London SE5 8AZ, 0800 731 2864).

Harm: In the event that something does go wrong and you or your child are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against your local NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential? All information which is collected about you during the course of the research will be kept strictly confidential. All your answers to the questionnaires and the activities will be kept on paper and on an electronic database. The recordings will be kept as electronic files. They will be kept securely and anonymously and will be identifiable only by a number, not by your name. Your name will be kept separately, with the number, on the database and on paper, so that we can identify your questionnaires and recordings in the future if we need to (for example, if you decide you no longer want to be part of the study). We will only identify your questionnaires for a reason like this. Paper copies of

questionnaires will be kept securely by the researchers in a locked filing cabinet in a locked office. Your details will be kept for up to 12 years, and then will be confidentially destroyed. We will keep a completely anonymised copy of the database indefinitely, from which you and your child will not be able to be identified at all.

The information you give will usually be available only to the research team. However, the researcher will let your team know that you are taking part in the study, and will share with your clinical team any important information that is relevant to the care you receive. In addition, should you give any information, such as criminal disclosures, or information relating to your own, your child's or others safety, which requires action, including passing on information to others, we are legally obliged to pass this information on to services who are able to deal with these concerns.

The recordings will all be confidential and will be kept without your child's name or details in a locked filing cabinet in a locked office, except when the therapist is carrying them to and from meetings. They will be available only to members of the research team.

What will happen to the results of the research study? We intend to publish the results of the research. You will not be personally identified in any report/publication. We sometimes use quotes from participants when we write about the research. In this case we will tell you what we want to write and where it will be seen and check that you agree.

Who is organising and funding the research? The research is organised by the team, who are members of academic and clinical staff at the Institute of Psychiatry, King's College London and the South London & Maudsley NHS Trust. The research is funded by the Guy's & St. Thomas' Charity.
Who has reviewed the study? The study has been reviewed by the North West London REC2: 11/LO/0023.

How can I take part? If you would like to take part in this project, please complete the attached consent form. If you have any questions or concerns about taking part in this study please contact the researchers below.
Contact Details:

Nedah Hassanali (Research Worker): Department of Psychology, King's College London, Institute of Psychiatry, Denmark Hill, London, SE5 8AF, Tel no: 0207 848 5794/ 07427475940

Karen Bracegirdle (Research Therapist): South London and Maudsley NHS Foundation Trust, Southwark Targeted CAMHS, 1st Floor Mapother House, De Crespigny Park, London, SE5 8AZ. Tel no: 0203 228 7777/ 07427425411

Information Sheet for Young People
V2 10th April, 2011

Coping with Unusual Experiences (CUES)

★ **What is this about?** We are asking if you want to be part of a project to find ways to help children or teenagers who have unusual experiences.

★ **Who are you? What do you do?** We work with children, teenagers and adults who are feeling upset or having problems and talk to them to find out what is upsetting them, then we help them find new ways to handle it.

★ **What are 'unusual experiences'?** Lots of children, teenagers and adults have these, and often they are not upsetting at all, but sometimes they can be. They are things like:

- ☞ *Hearing or seeing things that other people can't*
- ☞ *Feeling like something weird is going on that other people don't understand*
- ☞ *Feeling like someone is watching, or following you*

★ **Why are you asking me?** We are asking all children and teenagers aged 8-14 who come to this centre.

★ **What if I say yes?** First, we will ask you and your parent or carer some questions. This is to try to find out more about what causes unusual experiences and what makes them upsetting.

★ **What happens next?** If you say you have unusual experiences and you are feeling upset, we will ask you if you want to try out some new ways of trying to handle them.

★ **What if I say yes?** You will meet with someone who will talk to you about what is happening and ways to help. You will have up to 10 meetings, at a time and place that is good for you and your family. So we can see if the meetings are helpful, some people will have the meetings straight away, and some people will have them after 3 months.

★ **Will I have to wait?** You might. It is worked out by chance – a bit like tossing a coin. We can't choose who waits and who doesn't.

★ **Can I say no?** Yes, you can. It is up to you whether you join in. If you don't want to that is fine – no-one will mind and it won't change anything at school, at home or at the centre. Even if you say yes, you can still change your mind whenever you want and you don't need to tell us why.

★ **Who will know about this?** The things you tell us are private, but we will tell other people who are there to help if we are worried about whether you or someone else is safe.

★ **Can I find out more?** Yes. Ask your parents or carer. We have given them a longer sheet like this one that you can read if you want. If they agree, we can tell you more about joining in on the phone, or we can meet you to tell you more. You can meet us on your own or with your family – it is up to you and your parent or carer.

Thanks for reading the sheet

Appendix 6: Consent form for holders of parental responsibility

Institute of Psychiatry

at The Maudsley

South London and Maudsley NHS

Dr. Suzanne Jolley
PO77 Department of Psychology
Institute of Psychiatry
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Tel +44 (0) 20 7848 5028
Fax +44 (0) 20 7848 5006
Email: suzanne.jolley@kcl.ac.uk

KING'S College LONDON Founded 1829
University of London

CONSENT FORM – V2 10/4/2011

Title of project: **Coping with Unusual Experiences (CUES)**
Names of researchers: Karen Bracegirdle, Nedah Hassanali, Catherine Ames
Please initial boxes:

1. I have read the information sheet dated 10/4/11 for the above project, and one of the researchers has talked to me about it. I have had enough time to think about it and ask questions. ☐

2. I understand that taking part is voluntary and that my child and I are free to withdraw at any time, without giving any reason, and without our medical care or legal rights being affected. ☐

3. I am willing for the researcher to let the team know that my child and I are taking part in the study. ☐

4. I am willing for the researcher to contact my team with any information relevant to my child's care, should this become apparent while we are taking part in the study. ☐

5. I am willing for the researchers to record this information in the team's electronic notes for my child. ☐

6. I give permission for sections of my child's medical notes to be looked at by the researchers, if it is relevant to taking part in this research (for example, to get an address, age or confirm clinical information). ☐

7. I am willing for my and my child's meetings with the therapist and researcher to be audiorecorded. ☐

8. I understand that information relating to me and my child taking part in this study will be stored in an electronic file for up to 12 years. ☐

9. I agree to take part in the above study, and for my child to take part. ☐

Name of parent/carer	Date	Signature

10. I have explained the study to this participant and answered their questions honestly and fully. ☐

Name of researcher	Date	Signature

When completed, 1 copy for the family, 1 for researcher; 1 (original) to be kept in medical notes

Appendix 7: Assent form for young people

Institute of Psychiatry

at The Maudsley

South London and Maudsley NHS

Dr. Suzanne Jolley
PO77 Department of Psychology
Institute of Psychiatry
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Tel +44 (0) 20 7848 5028
Fax +44 (0) 20 7848 5006
Email : suzanne.jolley@kcl.ac.uk

KING'S College LONDON Founded 1829
University of London

ASSENT FORM for Young People – V2 10th April 2011
Coping with Unusual Experiences (CUES)

Names of researchers: **ID:**

Thank you for thinking about taking part in this project. The project must be explained to you before you agree to take part. If you have any questions please ask before you decide whether to join in. You will be given a copy of this form to keep.

Please tick the boxes, if you agree and the answer is 'yes':

1. I have read the Information Sheet for Young People, dated 10th April, 2011, and someone has explained it to me and answered my questions. ☐

2. I know that I can change my mind about joining in anytime and I don't have to say why. ☐

3. I know what I say is private unless it is about somebody being hurt. ☐

4. It is OK to record the meetings with me. ☐

5. I want to join in with the project. ☐

If any answers are 'no' or you don't want to join in, don't write your name. If you do want to join in, write your name on the line.

Young person's name: _____

Date:

6. I have explained the study and answered any questions. ☐

_____ _____ _____
Name of researcher Date Signature

When completed, 1 copy for the family, 1 for researcher; 1 (original) to be kept in medical notes

Appendix 8: Questionnaire of psychotic-like experiences

Unusual experiences questionnaire				
1. Some people believe that their thoughts can be read. Have other people ever read your thoughts?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
2. Have you ever believed that you were being sent special messages through the television?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
3. Have you ever thought that you were being followed or spied upon?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
4. Have you ever heard voices that other people could not hear?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
5. Have you ever felt that you were under the control of some special power?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
6. Have you ever known what another person was thinking even though that person wasn't speaking?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
7. Have you ever felt as though your body had been changed in some way that you could not understand?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
8. Do you have any special powers that other people don't have?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
9. Have you ever seen something or someone that other people could not see?		**Not true**	**Somewhat true**	**Certainly true**
If true, how often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal
10. If you have not had any of these experiences in the last 2 weeks, have you had any of them in the last year?		**Not true**	**Somewhat true**	**Certainly true**

Appendix 9: PLE appraisal items

Questions about your thoughts and beliefs.

From the different thoughts and beliefs we have talked about, which would you consider to be the main one?

☐ Believing that your thoughts can be read.

☐ Believing that you are being sent special messages through the television.

☐ Thoughts of being followed or spied upon.

☐ Hearing voices that other people cannot hear.

☐ Feeling that you are under the control of some special power.

☐ Knowing what another person is thinking even though that person isn't speaking.

☐ Feeling as though your body has been changed in some way that you cannot understand.

☐ Having special powers that other people don't have.

☐ Seeing something or someone that other people cannot see

Now thinking about this thought or belief....

Is it caused by something inside you or outside you?

5	4	3	2	1
Completely because of something outside	Mostly outside but some of it comes from inside	Mix of outside and inside	Mostly inside but some of it comes from outside	Completely because of something outside

Is it caused by events people can't control or by what other people are doing?

5	4	3	2	1
Completely what others do	Mostly what others do but some of it caused by other events	A mix of both	Mostly other events but some of it is caused by what others do	Completely other events

Is it dangerous to you or other people?

5	4	3	2	1
Yes, definitely	Slightly	A bit of both	Mostly harmless	No, completely harmless

Appendix 10: Stigma questionnaire

Alex is a new student in your class. Before they start, Alex explains that they have a mental health problem. Alex explains that this means they sometimes hear or see things which other people can't and that sometimes they think that people are spying on them or are out to get them, so sometimes Alex might not want to talk to anyone or might stay home from school.
Here are some sentences about Alex. Tick the box that comes closest to how much you agree with each sentence. There is no right or wrong answer; we would just like to know what you really think.

Alex can control their mental health problem

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Alex's problems are their own fault

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

I wouldn't mind spending time with Alex

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

I would let Alex join in with games

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

I would help Alex

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Alex is just like any other person in my class

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Please turn over

I would be scared of Alex

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

I would feel sorry for Alex

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Alex's problems would annoy me

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

I would be happy to be seen with Alex

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Alex is dangerous

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Alex belongs in a special school for people with mental health problems

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

It's best to avoid Alex

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Alex is unpredictable (you never know what he's going to do)

Definitely disagree	Partly Disagree	Don't Know	Partly Agree	Definitely Agree

Appendix 11: Modified and abbreviated ISMI

Here are some sentences about problems. Please circle how much you agree with each sentence about your problems.

1. People ignore me or take me less seriously just because I have problems

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

2. I am annoyed at myself for having these problems

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

3. I avoid trying to be friends with people who don't have my kind of problems because they wouldn't want to be friends with me

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

4. I don't mix with friends as much as I used to because my problems might make me look or behave 'weird'

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

5. Having these problems has spoiled my life

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

6. Others think that I can't do very much because I have these problems

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

7. I need others to make more decisions for me because of my problems

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

8. People with my kind of problems are usually violent

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

9. People with my kind of problems cannot live a good, happy life

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

10. I feel OK being out with a person who obviously has my kind of problems

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree

Appendix 12: Factor loadings for subscales of ISMI used as basis for abbreviation (from Ritsher et al., 2003)

Subscale	Item (paraphrased)	Factor loading for subscale
Alienation	*Disappointed in myself	0.85
	*Spoiled my life	0.67
	People without mental illness cannot understand me	0.37
	Embarrassed or ashamed	0.24
	Feel out of place in the world	0.22
	Feel inferior	0.21
Stereotype Endorsement	*Usually violent	0.68
	*Need others to make decisions	0.55
	*Cannot live good life	0.54
	Others can tell by the way I look	0.33
	I cannot contribute	0.30
	I should not get married	0.30
	Stereotypes apply to me	0.28
Discrimination Experience	*Others think I cannot achieve much	0.66
	People patronize me[1]	0.65
	*People ignore me	0.51
	People discriminate against me	0.31
	Nobody would want to get close to me	0.31
Social Withdrawal	*I do not socialise	0.62
	*Avoid getting close to people	0.55
	Feel out of place around others	0.51
	Stay away to avoid embarrassment	0.40
	Negative stereotypes keep me isolated	0.37
	I do not talk about myself much	0.32

* Item selected for abbreviated measure

[1] Item not selected on the basis of focus group – difficult to reliably explain and understand

N.B. Stigma resistance items were not included in the subscale factor analysis. Ritsher and colleagues (2003) suggest that the item 'comfortable to be with others with mental health problems' (paraphrased) is the one which most reliably loads onto the stigma resistance subscale when compared to other measures. This was therefore added to the measure.

Appendix 13: Consent form to take part in focus group

South London and Maudsley NHS
NHS Foundation Trust

Snowsfield Adolescent Unit
Mapother House
DeCrespigny Park
Camberwell
SE5 8AZ

Consent Form

I understand the aim of this focus group and that the information will be used for professional purposes. I understand that I can change my mind about joining the group at anytime and I don't have to say why. I understand information shared in the group will be kept anonymous.

I agree to take part in this focus group

Name:

Date:

Signature:

Appendix 14: Feedback form given to participants of focus group

Questions about our Questions

Did the questions make sense?

What did it feel like to answer the questions?

Were there any questions you thought shouldn't be there?

Were there any questions you would ask that aren't there?

Can you think of a better name for the boy in the class than John?

What else did you think about the questions?

Appendix 15: List of measures used in CUES (including those used in the present study)

Child Measures	Carer Measures
Strengths and Difficulties Questionnaire	Strengths and Difficulties Questionnaire
Ruminative Response Scale	Demographics Questionnaire
Spence Children's Anxiety Scale	Moods and Feelings Questionnaire
Short Moods and Feelings Questionnaire	Spence Children's Anxiety Scale
Rey Auditory Verbal Learning Task	Unusual Experiences Questionnaire
Means End Problem Solving Task	Early Child Development Questionnaire
Unusual Experiences Questionnaire	*Hospital Anxiety and Depression Scale
Self Reflection and Insight Scale	Five Minute Speech Sample
Peer Relationships Questionnaire	*The Brief COPE Inventory
Time Budget	*Warwick-Edinburgh Mental Well-being Scale
Jumping to Conclusions Questionnaire and Beads Task	*Social Support Questionnaire
Life Events Measure	
Brief Core Schema Scales	
PLE Appraisals	
Stigma Vignette and Questionnaire	
Modified Self-stigma of Mental Illness Questionnaire	
Familiarity Questionnaire	
Brief Illness Perceptions Questionnaire	

*Questionnaire relates to carer. For all other measures questionnaires refer to the child.

Appendix 16: Statistical analyses

16.1 *Spearman's correlation between age and primary measures*

		PLE Severity	Self-stigma	SO
Age	r_s	-0.10	0.05	-0.14
	P	0.56	0.82	0.44
	n	35	29	32

16.2 *ANOVA testing for gender differences on primary measures*

Measure	Levene's test statistic		t-test for equality of means		
	F	p	t	df	p
PLE Severity	3.03	0.09	-0.85	33	0.40
SO	2.49	0.13	0.37	30	0.71
SS	2.11	0.16	-0.18	27	0.86

16.3 *ANOVA testing for ethnicity differences on primary measures*

Measure	Levene's test statistic		t-test for equality of means		
	F	p	t	df	p
PLE Severity	0.54	0.47	0.19	33	0.85
SO	1.74	0.20	0.18	30	0.86
SS	1.68	0.21	-0.35	27	0.73

16.4 *Tests of normality, skew and kurtosis in data*

Measure	Kolmorgorov-Smirnov test	Shapiro-Wilk test	zSkewness	zKurtosis
Age	0.13	0.94	0.25	-1.68
PLE Conviction	*0.19	*0.89	**2.18	-0.14
PLE Frequency	*0.18	*0.86	1.56	-1.16
PLE Upset	*0.27	*0.78	**2.78	0.05
PLE Impact	*0.29	*0.77	**2.60	-0.35
PLE Severity	*0.19	*0.85	1.87	-1.15
SO	0.11	0.96	1.00	0.18
SS	*0.17	0.93	-1.36	-1.54
MFQ	*0.20	*0.88	**2.30	0.40
SCAS	0.09	0.97	1.29	0.11
SDQ Emotional Problems	*0.18	0.95	-0.74	-0.98
SDQ Conduct	*0.15	*0.93	0.72	-1.48
SDQ Hyperactivity	0.13	0.95	-0.53	-1.12
SDQ Peer Problems	0.14	0.96	0.17	-0.46
SDQ Prosocial Behaviours	*0.17	*0.90	-1.84	-0.50
SDQ Total Score	0.13	0.95	-0.92	-1.25
IPQ	*0.18	0.94	-1.33	0.30

* K-S or S-W statistic is significant at $p<0.05$ and therefore significantly deviates from a normal distribution.

**Z score for skew or kurtosis is greater than 1.96 and therefore significant at $p<0.05$.

16.5 *Descriptive statistics for subscales of the SCAS*

SCAS Subscale	Mean	Standard Deviation
Generalised Anxiety	7.03	3.71
Obsessive Compulsive	6.17	4.46
Panic	4.86	4.32
Separation Anxiety	5.14	3.34
Social Phobia	5.34	3.55

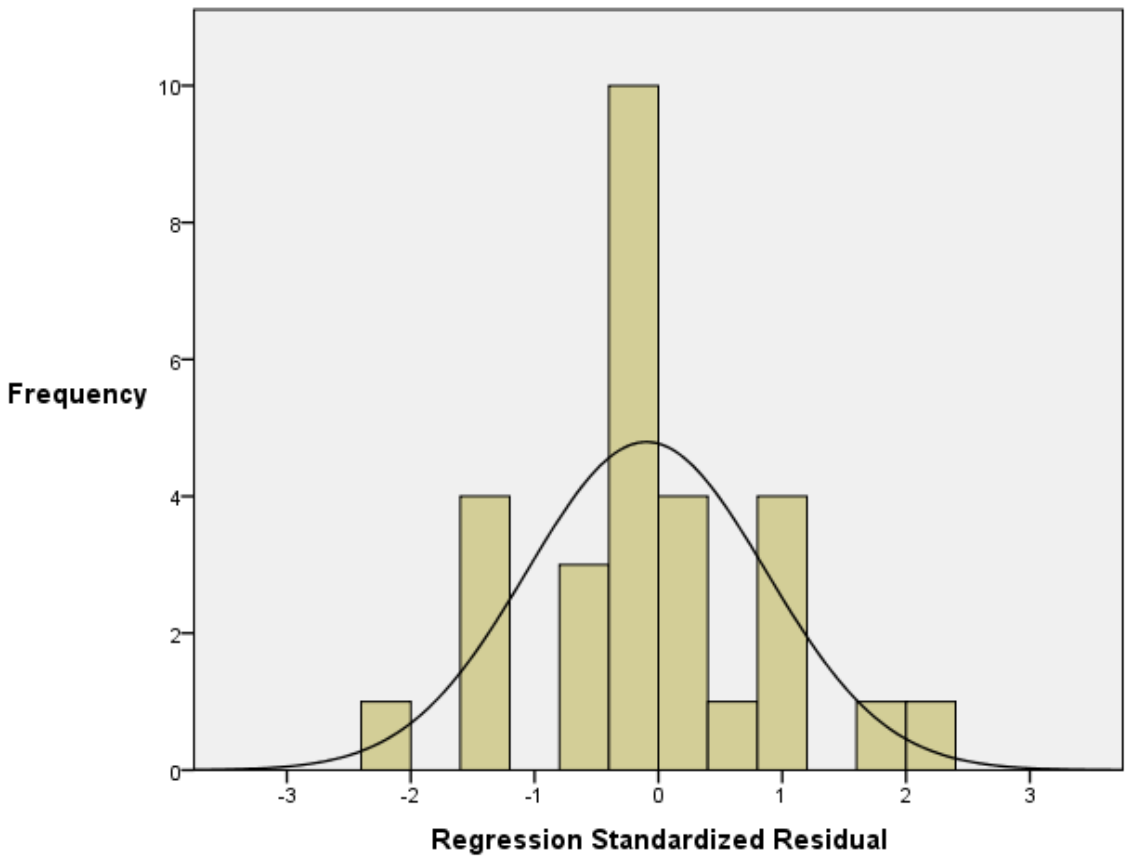
16.6 *Item-level descriptive statistics for the SO measure*

SO Item (paraphrased)	Mean	Standard Deviation
Alex can control problem	2.69	1.31
Problems are their own fault	2.09	1.30
Wouldn't mind spending time with Alex	2.19	1.31
Would let Alex join games	1.75	0.98
Would help Alex	1.66	0.90
Alex is just like anyone else	2.31	1.58
Scared of Alex	1.63	1.01
Sorry for Alex	1.84	0.99
Problems would annoy me	2.16	1.42
Happy to be seen with Alex	2.16	1.22
Alex is Dangerous	1.78	1.16
Alex belong in special school	2.84	1.61
Avoid Alex	1.97	1.33
Alex is unpredictable	3.31	1.09

16.7 *Item-level descriptive statistics for the SS measure*

SS Item (paraphrased)	Mean	Standard Deviation
People ignore me	2.62	1.35
I am annoyed at myself	2.93	1.62
I avoid making friends with people	2.17	1.34
I don't mix with friends as much	2.38	1.43
Problems have spoiled my life	2.66	1.57
Others think I can't do much	2.48	1.50
I need others to make decisions	2.03	1.27
People with my problems are violent	2.62	1.40
Cannot live a good, happy life	3.14	1.55
OK around someone with same problems	2.28	1.46

16.8 *Histogram of errors in residuals in regression model for PLE severity*



16.9 *Model summary and collinearity statistics for regression analysis*

	R	R Square	Adjusted R Square	Std. Error of Estimate	Durbin-Watson
Model 1	0.68	0.46	0.40	11.40	1.37

Model Summary

		Sum of Squares	df	Mean Square	F	Sig.
Model 1	**Regression**	2808.81	3	936.27	7.20	0.001
	Residual	3249.54	25	129.98		
	Total	6058.35	28			

ANOVA

Scale	Collinearity Statistics	
	Tolerance	VIF
SS	0.52	1.93
MFQ	0.44	2.28
SCAS	0.71	1.41